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ABSTRACT

The New York State Office of Mental Retardation and Developmental Disabilities initiated a project to produce a description of existing state and local programs and models of service delivery for early intervention services for children aged 0-5. A survey of 72 public and private service providers in 12 New York counties determined that 11,185 children were served, 15.9% of whom were identified as at risk for developmental delay. Early intervention services available were categorized as: entry services, direction services, and specialized services. Measures of capacity/coordination indicated that some counties needed increased capacity, and others showed a greater need for coordination than increased capacity. The largest single referral source was pediatricians. The mean age at start of services for all children in the sample was approximately 2 years, 6 months. The mean waiting time for services was approximately 1.5 months, while the median waiting time was 1 month. Inadequate transportation services did not appear to be a major problem. A rating of problems indicated that major problems were the lack of a legislative mandate which clearly indicates responsibility for this population and inadequate community education regarding the needs of disabled children and their families. (JDD)

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THE PRESCHOOL PUZZLE:
A Study of Early Intervention Programs and Services

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In the O.D. Heck DDSO, we wish to thank Fred Finn, Director of the O.D. Heck Developmental Center, and Ed Solomon, Treatment Team Leader, for providing us with the forum in that DDSO that drew providers together for our initial presentation. Their knowledge of the early intervention services and experts in the six O.D. Heck counties was immensely helpful in organizing and focusing our efforts in this project.

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EXECUTIVE SUMMARY

The New York State Office of Mental Retardation and Developmental Disabilities initiated a project in the fall of 1985 to examine early intervention services for children from birth to five years of age.

The goal of the project was to produce a description of existing state and local programs and models of service delivery. The specific foci were the relationships among the various service approaches and mechanisms, the local environments within which they function, and the ability of families with children with disabilities to find and use early intervention services.

The project was designed to describe the current system in terms of the following characteristics: the availability of services, the linkages among components of the system, and patterns of referral and service utilization.

PROJECT DESIGN

In order to achieve the goal outlined above, the project was designed to include:

An analysis of differences in the types and amounts of early intervention services and the organizations that provide or arrange for them in representative service areas of the state.

An examination of the sources and patterns of referral for children who have gained access to early intervention services.

An analysis of the impact of environmental and situational factors on access to early intervention services.

An inventory of the problems and opportunities that exist in the local arena of early intervention services.

The first phase of the study involved the identification and survey of all public and private agencies in each area providing early intervention services to determine:

- o The services provided and the numbers and ages of children served,
- o Waiting lists for program entry (where available),
- o Counties (areas) served,
- o The availability of summer programs, waiting lists for specific services, and unfilled program spaces.

The Broome and O.D. Heck DDSOs were chosen as representative of the various types of upstate counties across the state.

- o One hundred twenty-four agencies in those twelve counties were initially identified as service providers, and
- o A mail-in service inventory survey was used to collect information about the differences among services and providers.

Sources and Patterns of Referral

In order to examine important questions such as whether the source of referral to services or a child's home location in a service area had a significant impact on access to services, the second phase of the study involved a survey of a sample of children served by a sample of the agencies in these areas. The questionnaire covered such topics as:

- o Referral source,
- o Previous service history,
- o Age of the child at the time of starting the program,
- o Length of waiting time between referral and start of programming,
- o Home county of the child,
- o Transportation methods and problems for the child.

Environmental and Situational Factors

Characteristics of each county such as population size, density, population under five years old, income, percent urban, poverty level, education level, number of doctors and transportation methods were collected as well as the number of Family Court ordered service placements for preschoolers for each of the past five academic years.

Problem Inventory

Agencies selected for phase two of the study were also asked to complete a problem inventory rating the degree and frequency of a list of problems common to providers of early intervention services.

Key informant interviews were also conducted to identify the concerns and suggestions of knowledgeable and experienced actors in the field.

RESULTS

Differences Among Services and Providers

Number of children served

Seventy-two programs reported serving a total of 11,185 children:

- o 35% were between birth and two years of age;
- o 45% were between 3 and 5 years old; and
- o 19% were over 6 years old.

Many respondents indicated a substantial number of children were at risk for developmental delay, and while estimates of the number or percentage were not consistent, and some programs are reluctant to identify children as developmentally delayed or at risk, figures gathered from the survey responses indicate that 15.9% of the children are at risk. (See Table 1).

The number of children on known waiting lists is more than twice the number of available program spaces for children, but this varies widely from county to county. Some counties have more spaces for children than they have children on waiting lists.

Service Availability

One of the key findings of this study is that within the sizable array of services offered under the title of "Early Intervention Services," there is a way to map out these services and to organize them in a meaningful way. The three groups of services that we have discovered are:

Entry Services

Audiology
Diagnosis/
Assessment
Education
Funding
Psychology
Screening
Speech Therapy
Transportation

Direction Services

Advocacy
Case Management
Counseling
Info & Referral
Parent Training

Specialized Services

Occ. Therapy
Phys. Therapy
Respite

County of residence does not make a significant difference in the availability of most services. (See Table 2).

Because speech delay is often the least threatening and most acceptable (to

parents) category of disability recognized and funded under Family Court order, many programs use the diagnosis of speech delay in order to facilitate a child's entry into their program.

Direction Services focus primarily on the child's family. Many services are simply necessary in order for the child to receive other, more direct kinds of services such as those in the Specialized Services group. Yet these Specialized Services are much less available than the other groups of services.

Results of this study indicate that more trained professionals in the areas of occupational, physical, and speech therapy would improve the general availability of such services statewide.

Survey data did not support the idea that transportation services are significantly lacking.

Capacity/Coordination

The responses for number waiting and program slots available can be used to develop a measure of capacity/coordination for a particular county. Figure 5 illustrates the number of children on waiting lists and the number of program slots available. Table 3 lists the actual numbers in each category by county and shows the ratio of available spaces to the number waiting. Three counties, Broome, Chenango, and Schenectady, show a greater need for coordination than increased capacity. It should be cautioned, however, that many of the program spaces available might not be appropriate for all children on waiting lists.

Program directors informed us that it is often the policy of the program or agency not to create waiting lists or keep children on such lists. This study indicates that issues of capacity or coordination vary from county to county at least within OMRDD's service regions.

Sources and Patterns of Referral

Referral Sources

Overall, the largest single referral source was Pediatrician with 25% of the total number of referrals in the sample. (See Table 4).

- o Diagnostic Centers were the second largest source with 15.1% of the total, and Family/Self referrals accounted for 13.2% of those referred.
- o The Early Childhood Direction Centers had the lowest percentage of

referrals, accounting for only 3.8% of the total. However, the ECDCs may actually be "behind" many of the referrals from pediatricians and family/self.

- o Except for hospitals, referral source did not vary greatly by age group. Pediatricians, for example, referred nearly as many children over 2 and 1/2 years old as they did children under 2 and 1/2 years old.

The relatively low number of direct referrals from the Early Childhood Direction Centers is puzzling. By all accounts from key informant interviews and others (Davidson et al, 1984), this network of direction services constitutes a valuable resource and referral method. It is possible, and key informants concur, that a large number of referrals reported under family/self as well as a large proportion of referrals from pediatricians may be attributable in part to the work of the ECDCs.

It is clear from the diversity of responses to the Other category that there are many avenues by which children can reach agencies for services and programs.

Previous Services

Agencies reported that they were aware of previous service history for 145 children (68.4%) indicating that they did not know if the remaining 67 children (31.6%) had received previous services.

Most of those who had received services previously did so from another preschool program or received some type of medical service from a hospital, clinic, or public health program.

Age

The age at which these children began receiving services from the reporting agency ranged from 2 weeks old to 4 years, 10 months old.

- o The mean age at start for all children in the sample was just under 2 years, 6 months of age.
- o While there are some observable differences between counties for average starting age, these differences are not statistically significant.

Waiting Time

The mean waiting time was just over one and a half months, while the median waiting time was one month. Referrals by pediatricians, diagnostic centers, information and referral centers, and agencies' own efforts produce substantially different waiting times. (See Table 5).

- o Pediatrician referrals have on average a two week shorter waiting period than the sample mean of 1.52.
- o Children referred by diagnostic centers and information and referral centers, on the other hand, waited approximately one month longer overall than children from all other referral sources.

Referrals from pediatricians correlated significantly with shorter waiting times. Continued efforts to educate these physicians regarding the need for early programming for children with developmental delays should have a significant impact on improving the effectiveness of early intervention services.

Location

The children in the sample came from 22 counties.

- o 20.8% of the children were served in a county other than the county in which they lived.
- o Agencies in four counties reported serving no children from outside their home county.

Transportation Methods and Problems

Most providers did not see inadequate transportation services as a major problem. Responses to the Problem Inventory were consistent with the findings about the availability of transportation.

The three most frequently listed methods of transportation (vendor, agencies' own vehicles, and parent transporting) were almost equally utilized. The differences between the three methods were not significant.

Agencies identified only 25 of 188 children (13.3%) as having problems with transportation. About half of the problems overall (13 or 52%) are attributed to difficulties experienced with or by the parents. Only two problems (8%) involved children who lived outside of the county in which they received

services.

Anecdotal reports from key informants continue to mention the hardship imposed on very young children who must be transported long distances in order to attend a program which is center-based.

Problems and Opportunities

Respondents were asked to rate 26 problems and concerns using a scale ranging from "Not a Problem" to "Often a Major Problem." (See Table 6).

- o "The lack of a legislative mandate which clearly indicates responsibility for this population" and "inadequate community education regarding the needs of disabled children (0-5) and their families" were considered "Occasionally a major problem" overall.
- o "The absence of a single point of entry into the service system" was the problem which providers felt to be the least critical.

The kinds of problems faced by providers can be organized into three distinct categories: state level problems, local level problems, and problems that occur at the borders of interaction between the state and local levels. (See Table 7).

There are some patterns to the way in which the problems surveyed group together across county or DDSO lines. The Broome DDSO seems overall to have a greater concern with local issues than the O.D. Heck DDSO ranking local problems higher than state level problems in all six counties. State level problems are seen as more critical to three counties in the O.D. Heck DDSO, but two counties in this DDSO rank state level problems as the lowest.

Major problems identified by providers as local level problems may offer a focus for planning efforts to be directed by the state's lead agencies for children under 5 under P.L. 99-457, especially the problems of inadequate community education regarding the needs of disabled children 0-5 and lack of awareness among parents of community resources.

Conclusion

Early intervention services for very young children with developmental disabilities or delays are important and complex. This study should help to identify some of the major issues, problems and opportunities that can guide policy, planning and operational activity in the future.

INTRODUCTION

The New York State Office of Mental Retardation and Developmental Disabilities initiated a project in the fall of 1985 to examine early intervention services for children from birth to five years of age. The Program Research Unit of the Policy and Planning Office of OMRDD was given the task of exploring the existing system of services in order to inform key agency actors in the central and district offices about the issues to be addressed in dealing with this population. The project was also supported in part by a grant from the New York State Developmental Disabilities Planning Council.

ISSUES AND PROBLEMS

The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) serves a largely adult population of persons with developmental disabilities and operates or certifies relatively few regular and routine programs for children under the age of five. However, the agency has become increasingly involved in community-based programs; this has led to an interest in the well-being of persons of all ages with developmental disabilities who might be considered to be part of the OMRDD responsibility. Indeed, important elements of the Family Support Services programs funded and operated by OMRDD have been those serving families of very young children with disabilities. Consequently, the needs of families supporting a developmentally disabled child or relative and the needs of other unserved and underserved

groups of persons with developmental disabilities have become important concerns.

It was apparent that it would be necessary to learn more about the issues and problems in this area. It was also apparent from earlier research in this area (Bird, 1984) that this arena was characterized by complexity, duplication, and inequity in service availability, yet hundreds of millions of state and local dollars supported this service "system." The OMRDD's fiscal commitment is but a small percentage of the total dollars involved.

THE PROJECT'S GOALS AND OBJECTIVES

The goal of the project was to produce a detailed report describing existing state and local programs of service delivery for children from birth to five in two regions of the state. This information would assist this and other agencies to identify some of the issues and factors that affect early intervention services on a statewide basis. At the local level, this information would be useful to advocates, planners and providers in identifying possible ways to enhance the capacity, coordination, comprehensiveness and timeliness of the services in their locale as well as offer comparisons to other counties and regions.

The report was designed to describe the current system in terms of the following characteristics: the availability of services, the linkages among

components of the system, and patterns of referral and service utilization. The specific foci were the relationships among the various service approaches and mechanisms, the local environments within which they function, and the ability of families with children with disabilities to find and use early intervention services. In addition, problems that plague the current system were to be identified and their relationships to the service environment were to be analyzed.

PROJECT DESIGN

In order to achieve the goals and objectives outlined above, the project was designed to include:

An analysis of differences in the types and amounts of early intervention services and the organizations that provide or arrange for them in representative service areas of the state.

An examination of the sources and patterns of referral for children who have gained access to early intervention services.

An analysis of the impact of environmental and situational factors on access to early intervention services.

An inventory of the problems and opportunities that exist in the local arena of early intervention services.

DIFFERENCES AMONG SERVICES AND PROVIDERS

Site Selection

To examine differences in the types of early intervention services

available and the organizations involved in their provision, it was decided to examine these phenomena in two District Developmental Services Offices. Each DDSO was comprised of six counties which were representative of both the urbanized and rural areas of upstate New York with wide variation in income, education, poverty levels, and the number of doctors available. (See Figures 1a and 1b). Within those twelve counties, every program that could be identified as possibly serving the disabled preschool population was contacted and invited to participate in the study.

Phase One

In order to describe the current array of early intervention services and to assess whether there were significant differences in the types and amounts of services available by region, the first phase of the study involved the survey of all public and private agencies in each of the two target DDSOs which provided early intervention services to preschool children.

One hundred agencies in those twelve counties were initially identified as service providers by a peer review and list collating process. An additional twenty-four programs were included in the initial survey: twelve Infant Health Assessment Programs - IHAPs (one per county) and twelve Family Courts (one per county). These 124 agencies were mailed a service inventory survey which asked them to describe their program in terms of:

- o The services provided and the numbers and ages of children served,

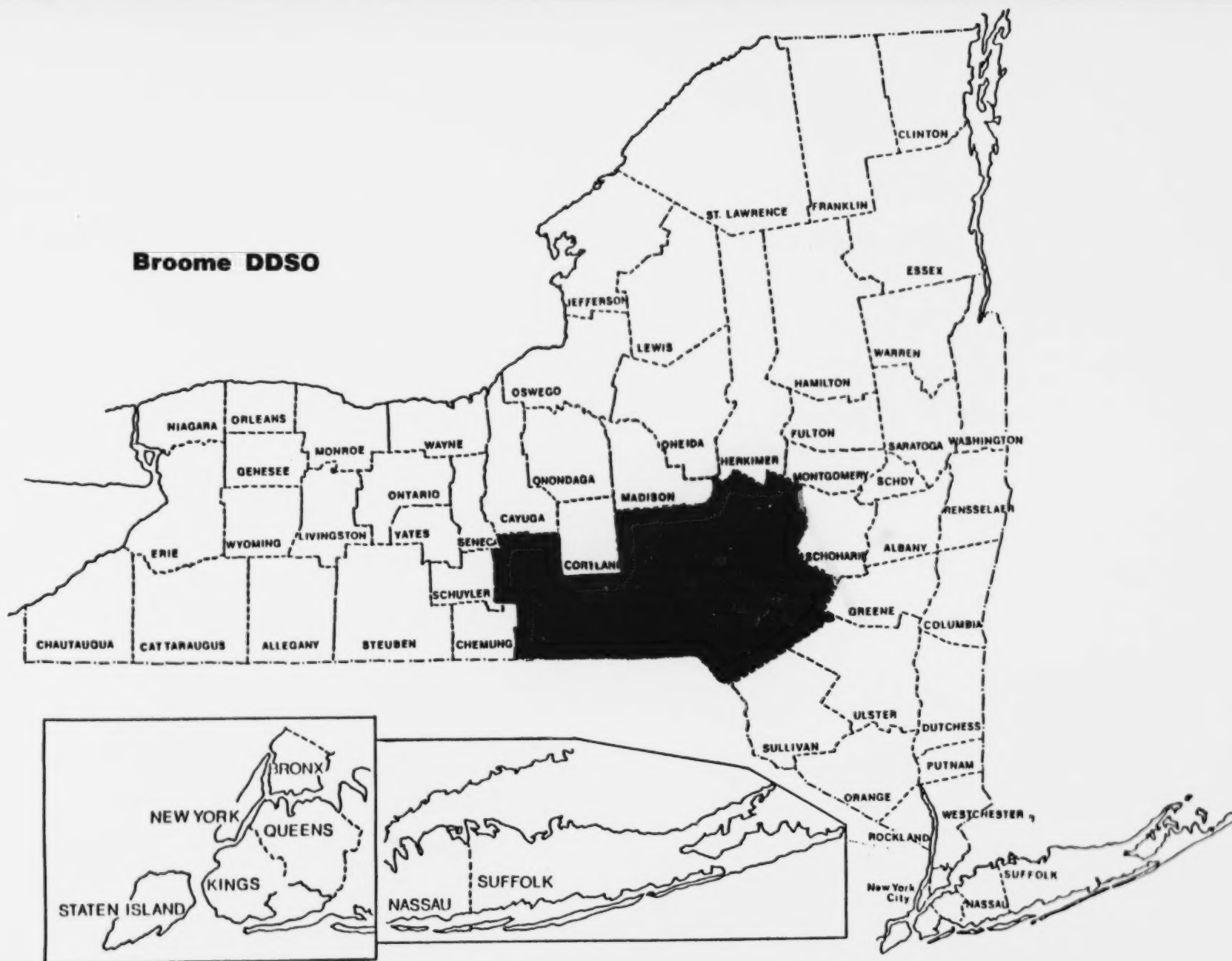


FIGURE 1a

O.D. Heck DDSO

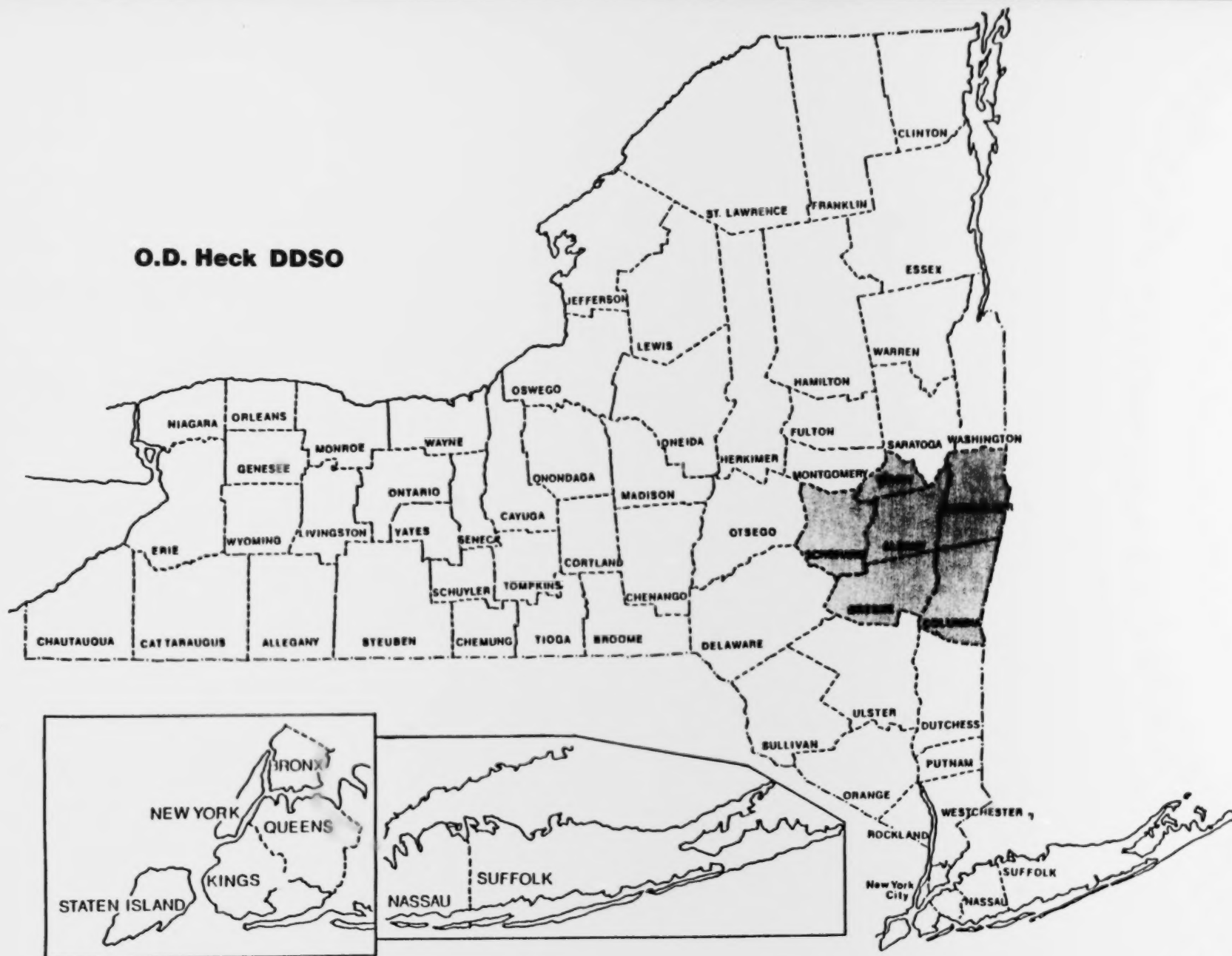


FIGURE 1b

- o Waiting lists for program entry (where available),
- o Counties (areas) served,
- o The availability of summer programs, waiting lists for specific services, and unfilled program spaces.

SOURCES AND PATTERNS OF REFERRAL

Phase Two

In order to examine important questions such as whether the source of referral to services or a child's home location in a service area had a significant impact on access to services, the second phase of the study required a survey of a sample of children served by a sample of the agencies in these areas to determine:

- o Referral sources,
- o Previous service history,
- o Age of the child at the start of the program,

- o Length of waiting time between referral and start of programming,
- o Home location of the child,
- o Transportation methods and problems for the child.

Sampling Procedure

To obtain this child-specific data, a random sample of 27 programs was drawn from the agencies who responded to the phase one survey. These agencies were asked to provide anonymous information about a random sample of children with developmental delays served by their programs. Twenty percent of this population (or 231 children) was selected and surveyed by these 27 agencies using a brief mail-in questionnaire for each child. Each agency received directions with the questionnaires on how to ensure the randomness of the sample of children.

ENVIRONMENTAL AND SITUATIONAL FACTORS

Demographic information and a service system indicator for the counties in each DDSO were gathered to describe more completely the context of services and to assess the degree, if any, to which these environmental factors affect service availability and accessibility.

Data were compiled from sources which included U.S. Census reports (City and County Data Book) and the NYS Education Department. Both sources were used to create profiles of the twelve counties involved in the study.

Characteristics of each county such as population size, density, population under five years old, income, percent urban, poverty level, education level, number of doctors and transportation methods were recorded as well as the number of Family Court ordered service placements for preschoolers for each of the past five academic years.

PROBLEM INVENTORY

All agencies selected for phase two of the study were also asked to complete a problem inventory. They were asked to rate the degree and frequency of a list of problems common to providers of early intervention services as derived from a group planning exercise in Monroe County. In addition to the problem inventory completed by individual agencies, key informant interviews were conducted with persons identified by our DDSO representatives as the most knowledgeable and experienced actors in the field. Fourteen agency directors and other experts were visited and interviewed by a member of the project staff regarding their suggestions for solutions to the various problems identified and included in the problem inventory.

REVIEW OF RESPONSES

Eighty agencies and sixteen IHAP or Family Courts responded to the service inventory (80% and 66.6% respectively). As the information from the eighty agency responses was reviewed, it was determined that several programs had been inappropriately identified as serving the target population. A total of fifteen programs responding failed either to serve the age group specified, provide the services we were interested in studying, or serve children who could be identified as developmentally delayed. (This presented an interesting comment on the ways in which these programs were perceived by other providers in the county or DDSO.) One response was received from a program that had not been mentioned by any of the providers in collating the original lists. These changes meant that an amended list of agencies to be surveyed consisted of 86 agencies. Of these, a total of 66 (or 76.7%) responded. Two programs in the same agency were later combined to yield a total N of 65 agencies.

A review of the Family Court and IHAP responses indicated that inclusion of the Family Court numbers of children served would be duplicative, because all children listed by the Courts would be receiving services from one or more of the providers already surveyed. The IHAP figures might or might not be duplicative, but because these programs were so new, it was felt that the children listed as served would be less likely to be in another service program. The decision was made to include the IHAP programs' services and numbers in the survey results but to exclude the figures provided by the Family Court respondents. Many of their comments and responses were extremely helpful and enlightening in other ways, however. A total of seven (out of twelve) IHAP

programs were finally added to the number of agencies and programs analyzed, yielding an N of 72 for a response rate of 73.4% (72/98) from programs and agencies in the first phase of the study. Figure 2 illustrates the number of responses for each county in the study.

Response to Inventory



FIGURE 2

RESULTS

The results of the study are organized as follows:

DIFFERENCES AMONG SERVICES and PROVIDERS (Program Characteristics):

Numbers of children served

Service availability

Service groups

Capacity and coordination

SOURCES and PATTERNS of REFERRAL (Child Specific data):

Referral sources

Previous services

Age

Waiting time

Location

Transportation methods and problems

PROBLEMS and OPPORTUNITIES (Provider concerns):

Major and minor problems

Problem groups

DIFFERENCES AMONG SERVICES AND PROVIDERS (Program Characteristics)

Number of Children Served

Seventy-two programs reported serving a total of 11,185 children; 3,935 (35%) were between birth and two years of age; 5,007 (45%) were between 3 and 5 years old; and 2,141 (19%) were over 6 years old. Some confusion over the age cut-off between 2 and 3 years of age may account for the difference (102) between the three age groups' total and the total number reported served. Three thousand three hundred and eighty children (30.2%) were identified as developmentally delayed. Many respondents indicated a substantial number of children were at risk for developmental delay, and while estimates of the number or percentage were not consistent, and some programs are reluctant to identify children as developmentally delayed or at risk, figures gathered from the survey responses total 1,778 (15.9%) children at risk. (See Table 1).

Five hundred eighty (580) children were listed as currently on waiting lists for programs, and two hundred fifty-one (251) program spaces for children were unfilled in other programs. Just over one in five programs (20.8%) indicated that they had children in their program who were waiting to receive specific services, usually occupational therapy, physical therapy or speech therapy.

The majority of programs (76.4%) indicated that they provided services during the summer as well as the school year. Figure 3 illustrates the availability of summer programs by county.

Table 1
NUMBER OF CHILDREN IN SURVEYED AGENCIES AND PROGRAMS

	<u>N</u>	<u>%</u>
Total number served (72 agencies)	11,185	100
Ages 0-2	3,935	35
Ages 3-5	5,007	45
Over 6 years old	2,141	19
Developmentally delayed	3,380	30
At risk*	1,778	--
Number on waiting lists to enter program	580	--
Number of program spaces available	251	--

*Estimates not provided by all respondents.

SUMMER PROGRAMS OFFERED

(Summer Program Avail.?)

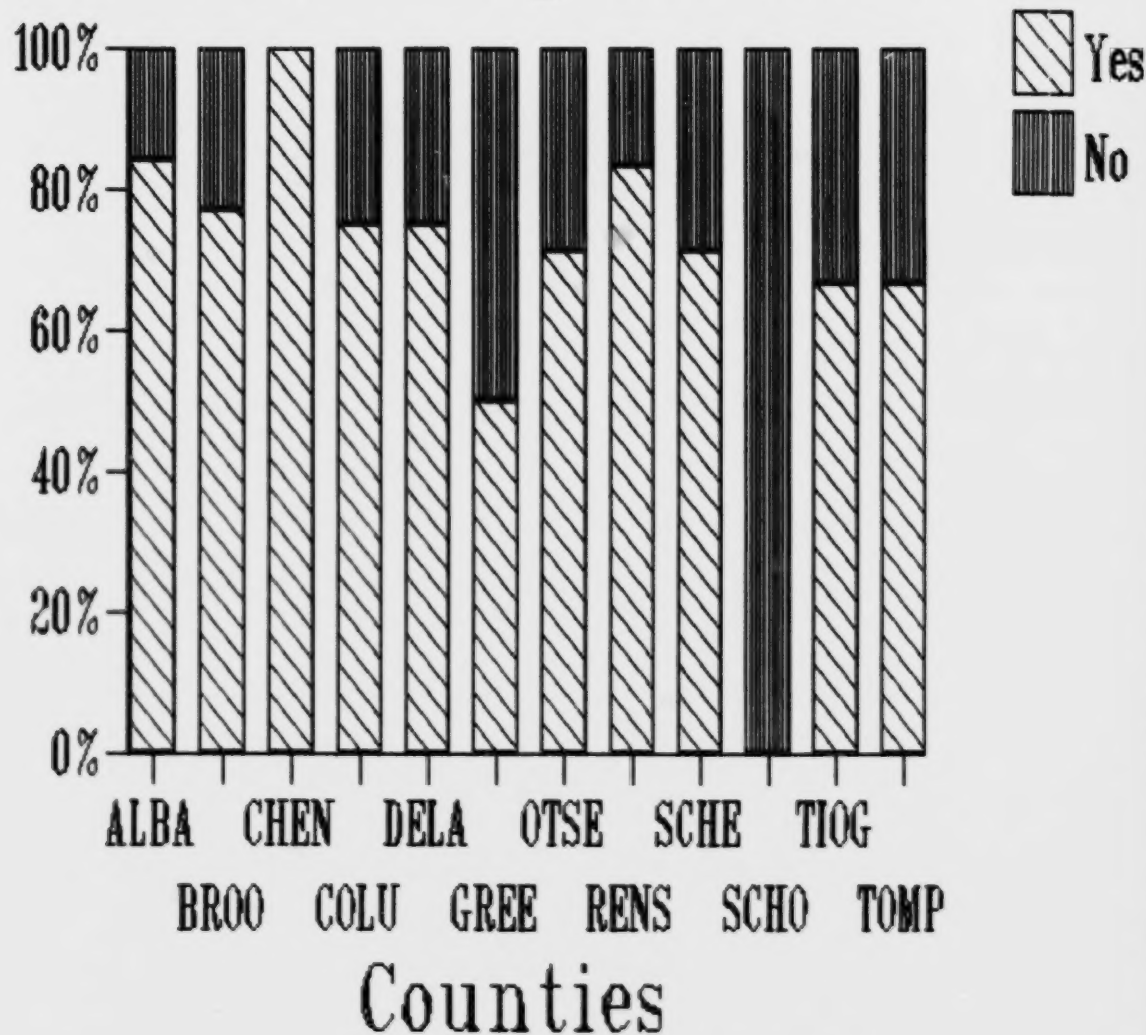


FIGURE 3

Service Availability

As part of the survey, agencies were asked to indicate which services they offered from the list in Table 2. Table 2 shows the frequency of services offered as a percentage of the total number of agencies answering 'Yes' for that service (% Yes Overall) and the availability of each service within each county as a percentage of the agencies offering the service within that county. Table 2 also shows that several counties indicate no availability of some services. Other services are available through any agency in those counties.

Overall, a little over 10% of the variance in service availability is due to county location, indicating only small differences among our 12 sample counties in this respect. That is, the county does not make a significant difference in the availability of most services. The Eta² statistic may be interpreted as the proportion of variation in service availability accounted for by county effect. While nearly a quarter of the variance in the availability of Occupational Therapy (Eta² = .23) is attributable to county of location, for example, the mean Eta² for all services is only .13.

Service Groups

A factor analysis was performed on the services data to determine if there

Table 2
SERVICES OFFERED BY COUNTY
County (n of agencies)

Services	% Yes Overall	Alba(19)	Broo(13)	Chen(3)	Colu(4)	Dela(4)	Gree(2)	Otse(7)	Rens(6)	Sche(7)	Scho(1)	Tiog(3)	Tomp(3)	Eta ^{2*}
Advocacy	75%	79%	54%	67%	100%	75%	100%	71%	100%	71%	100%	67%	67%	.11
Audio	29%	32%	23%	33%	0%	50%	50%	14%	16%	43%	100%	0%	67%	.15
Case Man.	64%	63%	54%	67%	100%	25%	50%	57%	67%	71%	100%	100%	67%	.11
Counsel	67%	74%	54%	100%	50%	75%	0%	71%	67%	71%	100%	67%	67%	.11
Diagnosis	74%	68%	62%	100%	75%	50%	100%	71%	100%	71%	100%	67%	100%	.11
Education	68%	63%	62%	100%	50%	50%	100%	43%	100%	71%	100%	100%	67%	.15
Funding	53%	42%	23%	67%	50%	75%	100%	57%	50%	71%	100%	100%	67%	.18
I & R	86%	84%	69%	100%	100%	75%	100%	86%	100%	100%	100%	67%	100%	.12
Medical	51%	47%	46%	67%	50%	50%	50%	43%	50%	43%	100%	100%	67%	.07
O.T.	39%	32%	15%	100%	50%	25%	50%	14%	50%	71%	0%	67%	67%	.23
Parent Trng	67%	53%	62%	100%	75%	75%	100%	29%	100%	71%	100%	100%	67%	.20
P.T.	36%	32%	31%	33%	50%	25%	50%	29%	50%	43%	0%	33%	67%	.05
Psychology	50%	47%	38%	100%	0%	50%	100%	43%	67%	71%	100%	33%	33%	.19
Respite	.08%	.08%	11%	33%	25%	0%	0%	14%	0%	0%	0%	0%	0%	.09
Screening	71%	68%	46%	67%	75%	50%	100%	71%	100%	86%	100%	100%	67%	.15
Social Wk	53%	63%	46%	67%	25%	50%	50%	57%	50%	29%	100%	67%	67%	.08
Speech Ther	71%	68%	62%	100%	75%	75%	100%	43%	83%	71%	100%	67%	100%	.10
Transport.	50%	53%	31%	67%	25%	50%	100%	57%	67%	29%	100%	67%	67%	.13

* Mean value of Eta² for all services = .13

were core groups of services offered with patterns of service availability among agencies. One of the key findings of this study is that within the sizable array of services offered under the title of "Early Intervention Services," there is a way to map out these services and to organize them in a meaningful way. The majority of services studied presented themselves in terms of three factors shown below.

<u>Group 1</u>	<u>Group 2</u>	<u>Group 3</u>
Entry Services	Direction Services	Specialized Services
Audiology	Advocacy	Occ. Therapy
Diagnosis/ Assessment	Case Management	Phys. Therapy
Education	Counseling	Respite
Funding	Info & Referral	
Psychology	Parent Training	
Screening		
Speech Therapy		
Transportation		

(These three factors explained 51.8% of the total variance in services offered. Social Work and Medical Services did not load singularly.)

Examination of the service groups indicated that Group 1 might be considered Entry Services since they have to do primarily with provider

activities that result in an evaluation of the child and determination of appropriate services and funding avenues. Group 2 suggests Direction Services which might be offered to families who are looking for assistance in dealing with the child's developmental delay or in locating a program for their child. Group 3 are fairly specialized services for children who have significant physical and developmental needs and have been named Specialized Services for the purposes of this report.

Speech therapy may seem incongruous as a part of the group of services called Entry Services, yet anecdotal reports from key informants indicate that Speech Delay is often the least threatening and most acceptable (to parents) category of disability recognized and funded under Family Court order. Many programs use the diagnosis of Speech Delay in order to facilitate a child's entry into their program. Audiology is often a screening service which serves a similar function, according to these same informants.

Many activities that are considered Early Intervention services indirectly involve the child. Direction Services, for example, focus primarily on the child's family. Many services are simply necessary in order for the child to receive other, more direct kinds of services such as those in the Specialized Services group. Yet these Specialized Services are much less available than the other groups of services.

Three service index scores were developed from these groupings. For each agency, the number of services provided in a given group was divided by the total number of possible services in that group and multiplied by 100. A high score means only that most of the services in a given array are offered by that agency. This serves to gauge the strength of an agency's role in providing a

certain type of service but does not specifically pertain to the availability of any one particular service. For example, a score of 80% in the Direction Services group means that an agency offers 4 of the 5 services listed in that group, but does not tell which of the services are provided. For the individual distribution of service availability by county, please refer back to Table 2.

These service index scores were then computed for each county by averaging the scores of each group of services for all agencies responding from that county. A mean score of 16.67% in Specialized Services in Delaware County, for instance, indicates a relatively low availability of this type of service among agencies in that county. However, availability measures mean only that agencies provide the service. Even a relatively high degree of availability does not necessarily mean that such services are easily accessible, particularly in rural areas where only one or two agencies provide these services and operate at full capacity.

Figure 4 illustrates the availability of these service groups as offered in each of the counties in the study. Except for Greene and Schoharie counties, Direction Services are more available than either Entry or Specialized Services. Specialized Services are the least available group of services. Specialized Services are not offered by the responding agency in Schoharie County, but only one agency (out of two) identified for that county responded to the survey. It is not known if those services are offered by the program that did not respond, but since that program is a satellite of the United Cerebral Palsy Association of Schenectady, those services are probably available through that program.

SERVICES INDEX

% offering service group

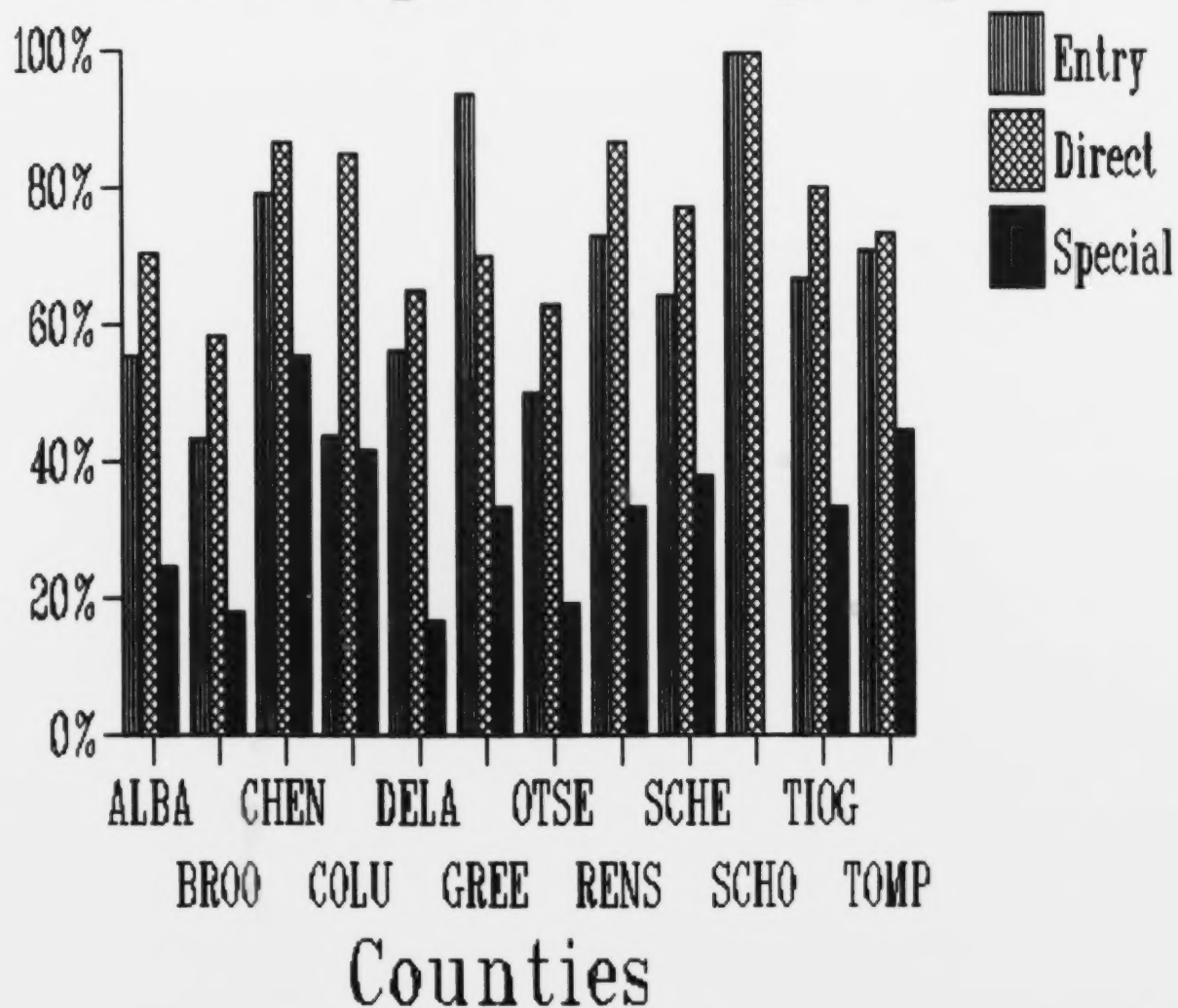


FIGURE 4

Capacity/Coordination

The responses for number waiting and program slots available can be used to develop a measure of capacity/coordination for a particular county. If more children are waiting than there are spaces available for them, then the need is for more capacity to accommodate those waiting. If, on the other hand, the number of program spaces available approaches or exceeds the number of children waiting, then the need is for more coordination among providers to move those on waiting lists into existing spaces. Figure 5 illustrates the number of children on waiting lists and the number of program slots available. Table 3 lists the actual numbers in each category by county and shows the ratio of available spaces to the number waiting. Ratios close to zero indicate a greater need for more capacity in a county's programs, while ratios approaching and exceeding 1 (100%) indicate that the number waiting and the number of available spaces could be matched assuming more coordination among providers. For example, in Greene County, there are program spaces available for only 10% of those waiting. Conversely, in Broome County there are nearly 2 and 1/2 times more program slots than there are children waiting for programs.

Summary

Early intervention services can be organized into three groups of services, some of which focus primarily on the child's family, some of which facilitate a child's entry into a service program, and some of which are direct services to

Capacity - Coordination

waiting, slots avail.

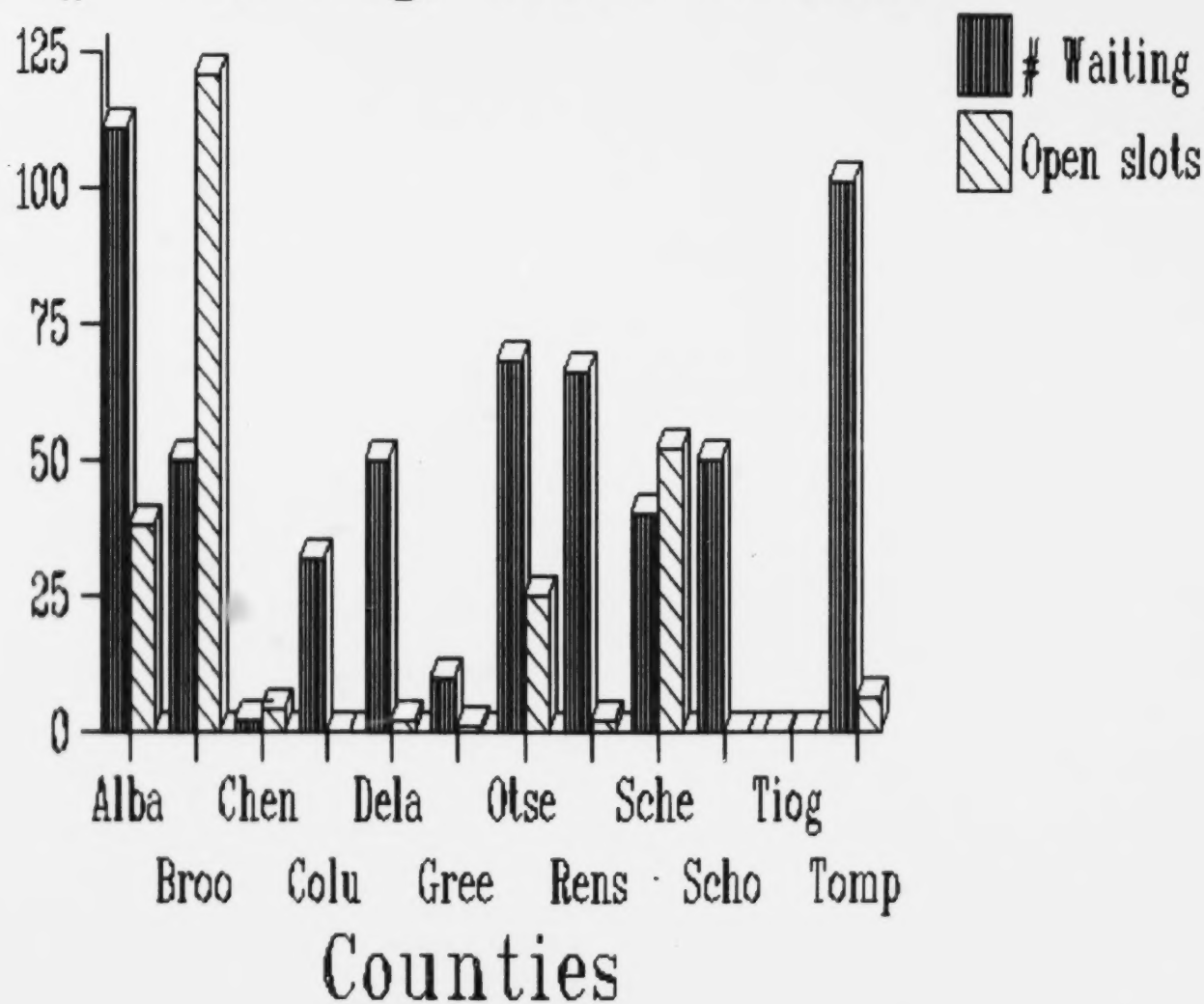


FIGURE 5

Table 3
PROGRAM SLOTS AND NUMBERS ON WAITING LISTS

<u>Counties</u>	<u>Spaces available</u>	<u>Number waiting</u>	<u>Ratio (Spaces/# waiting)</u>
Albany	38	111	.34
Broome	121	50	2.42
Chenango	4	2	2.00
Columbia	0	32	0.00*
Delaware	2	50	.04
Greene	1	10	.10
Otsego	25	68	.37
Rensselaer	2	66	.03
Schenectady	52	40	1.30
Schoharie	0	50	0.00**
Tioga	0	0	0.00***
Tompkins	6	101	.06

*Number waiting represents 1% of county pop. under 5 years old.

**Number waiting represents 3% of county pop. under 5 years old.

***Programs reported no children waiting and no spaces available.

the child. Many services, such as those called Entry Services and Direction Services, are more available than Specialized Services such as occupational therapy, physical therapy, and respite. Speech therapy is usually offered along with other Entry Services. High service availability within a county may not mean that services are also easily accessible for children. Some counties indicate that they have many more children on waiting lists than there are program spaces available, but other counties have room to accommodate more children than they are presently serving.

SOURCES AND PATTERNS OF REFERRAL (Child Specific Data)

The second phase of the study involved the random selection of agencies to provide anonymous data about children in their programs. The probability of an agency's selection was related to the relative size of its developmentally delayed population. Each agency selected was asked to survey twenty percent of the children with developmental delays which it served. Twenty-seven agencies were selected and asked to provide information on a total of 231 children with developmental delays. Of these 27, twenty-five (92.5%) responded with data about 212 children (91.7%).

Referral Sources

One of the key pieces of data provided by reporting agencies was the

referral source for each child in the sample. Agencies were asked to identify which of the following sources referred the child to the agency:

1. Early Childhood Direction Center
2. Pediatrician
3. Diagnostic Center
4. Hospital (if other than the Diagnostic Center above)
5. Information and Referral Center
6. Another preschool program
7. Family/self referral
8. Other

Table 4 and Figure 6 present the findings for referral sources. Overall, the largest single referral source was Pediatrician with 53 (25%) of the total number of referrals in the sample. Diagnostic Centers were the second largest source with 32 (15.1%) of the total, and Family/Self referrals accounted for 28 (13.2%) of those referred. Interestingly, the Early Childhood Direction Centers had the lowest percentage of referrals, accounting for only 8 cases or 3.8% of the total. This probably reflects the indirect nature of much of the work of the ECDCs in providing direction services to families and professionals who are looking for an appropriate program or services for a child. It is suspected that the ECDCs are actually "behind" many of the referrals from pediatricians and family/self. The survey instrument, however, directed providers to indicate which of the sources listed above "referred the child to this program." It could not ask how the source might have found out about the program.

TABLE 4
REFERRAL SOURCES BY COUNTY

Percent of referrals from each source

	<u>Overall</u>	<u>Albany</u>	<u>Broome</u>	<u>Chen.</u>	<u>Colum.</u>	<u>Dela.</u>	<u>Greene</u>	<u>Otsego</u>	<u>Rens.</u>	<u>Schen.</u>	<u>Schoh.</u>	<u>Tioga</u>	<u>Tomp.</u>
ECDC	3.8%	0.0%	1.8%	0.0%	0.0%	0.0%	0.0%	0.0%	22.7%	0.0%	0.0%	20.0%	5.6%
Pediatrician	25.0%	29.6%	36.4%	0.0%	12.5%	9.1%	0.0%	12.5%	22.7%	0.0%	0.0%	0.0%	22.2%
Diag. Ctr.	15.1%	16.9%	12.7%	50.0%	0.0%	0.0%	0.0%	0.0%	22.7%	50.0%	0.0%	40.0%	11.1%
Hospital	6.1%	12.7%	0.0%	0.0%	25.0%	0.0%	0.0%	12.5%	4.7%	0.0%	0.0%	0.0%	0.0%
I&R Ctr.	5.2%	1.4%	1.8%	0.0%	25.0%	36.4%	0.0%	0.0%	0.0%	0.0%	0.0%	20.0%	11.1%
Preschool	11.8%	9.8%	12.7%	0.0%	0.0%	18.1%	0.0%	12.5%	13.6%	0.0%	0.0%	20.0%	22.2%
Family/Self	13.2%	14.1%	10.9%	33.3%	12.5%	18.2%	100.0%	25.0%	0.0%	0.0%	0.0%	0.0%	16.7%
Other	19.9%	15.5%	23.7%	16.7%	25.0%	18.2%	0.0%	37.5%	13.6%	50.0%	100.0%	0.0%	11.1%
Total %	100.0%*	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
N of children	212	71	55	6	8	11	2	8	22	2	4	5	18

"OTHER" CATEGORY BREAKDOWN

DSS	4.7%	0.0%	9.1%	0.0%	12.5%	9.1%	0.0%	12.5%	9.1%	0.0%	0.0%	0.0%	0.0%
Other Health	5.7%	4.2%	9.1%	16.7%	12.5%	0.0%	0.0%	0.0%	0.0%	50.0%	0.0%	0.0%	5.6%
Agency efforts	5.7%	11.3%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	0.0%	100.0%	0.0%	0.0%
Other	3.8%	0.0%	5.5%	0.0%	0.0%	9.1%	0.0%	25.0%	4.5%	0.0%	0.0%	0.0%	5.6%

*Computer rounding - figures add to 100.1%.

REFERRAL SOURCES

(N = 212)

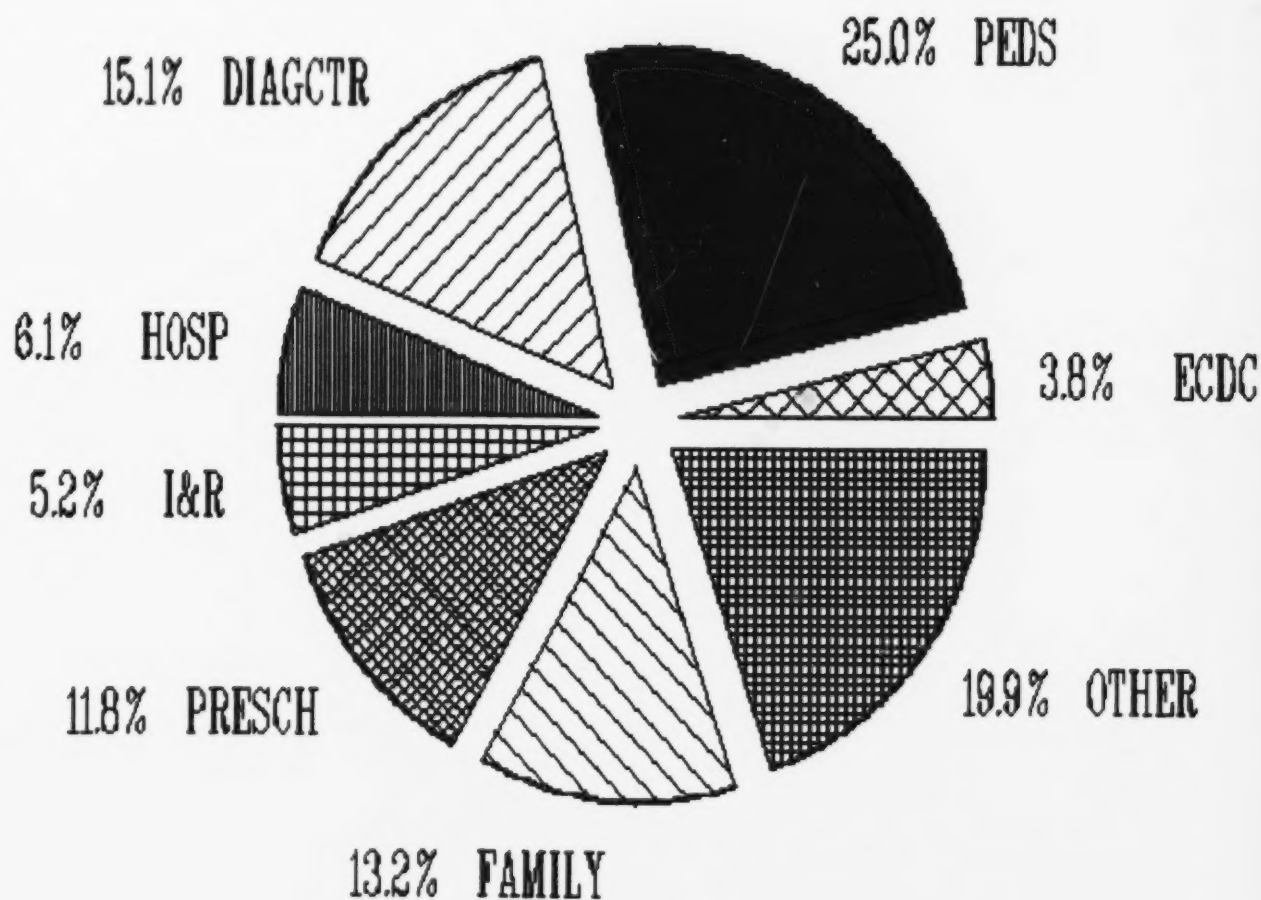


FIGURE 6 43

A large number of original responses (51 or 24%) were considered Other by the responding agencies. Respondents were asked to specify these sources. A review of the sources specified allowed several to be recategorized, and the remainder were broken out into three distinct new groups and a smaller Other category (bottom of Table 4). The new groups included: the Department of Social Services, other health professionals and programs, and agencies' own efforts at screening.

Figure 7 shows the size of these groups in relation to the original sources listed on the survey. The reduced Other category included one response listing a real estate agent as the referral source for a child whose parents were relocating to the study area. It is clear that there are many avenues by which children can reach agencies for services and programs.

Only 12 children (5.7%) had a second referral source listed on the survey. These were fairly evenly distributed among the original categories from Pediatrician to Other (Choices 2-8).

Previous Services

Agencies were asked if they knew of previous services that the child had received and, if yes, to identify those services. Agencies reported that they were aware of previous service history for 145 children (68.4%) indicating that they did not know if the remaining 67 children (31.6%) had received previous services. Of the 145 children whose previous service history was known, 56 (38.6%) were known to have received no prior services. For the 89 children

NEW REFERRAL SOURCES

N = 212

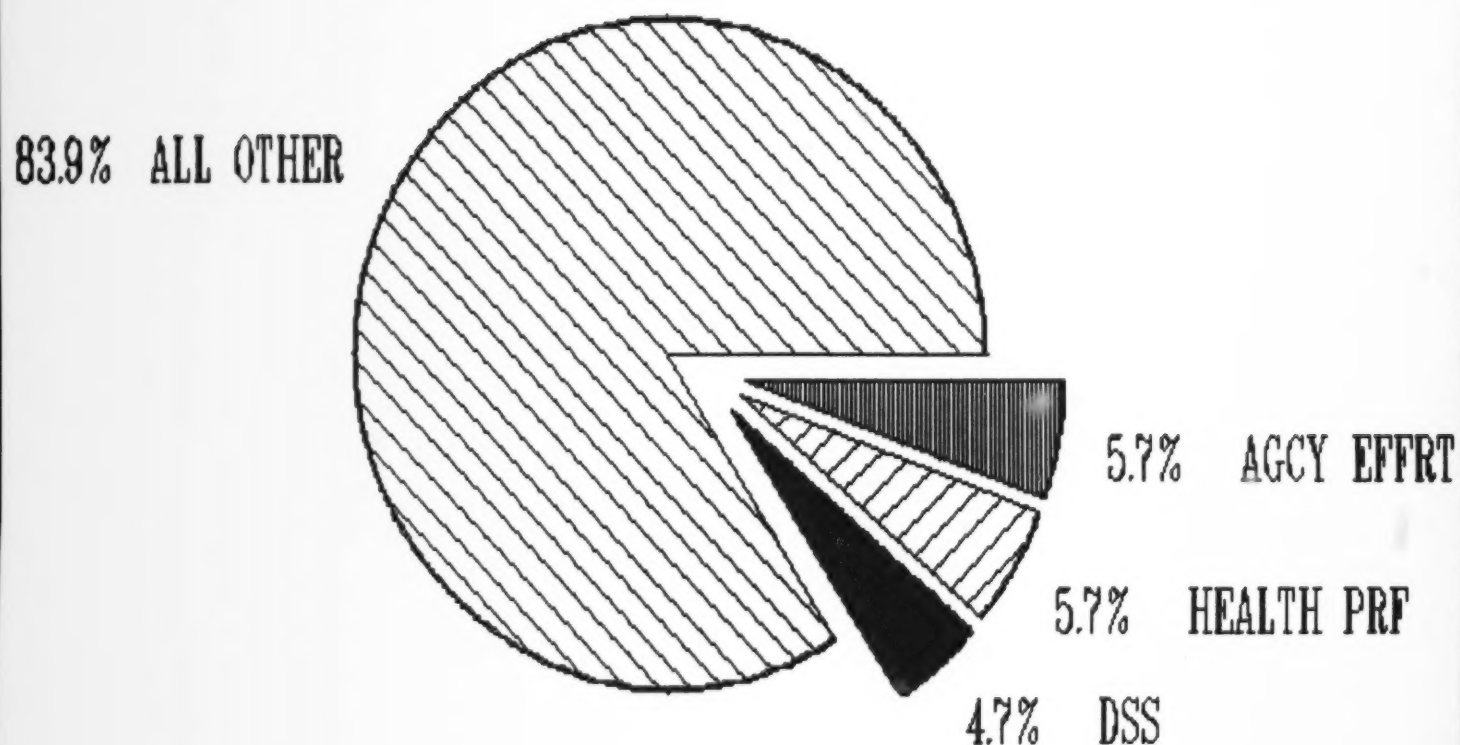


FIGURE 7

(61.4%) who had received service prior to entering the responding agency's program, most received services from another preschool program or some type of medical service from a hospital, clinic, or public health program.

Age

The age at which these children began receiving services from the reporting agency ranged from 2 weeks old to 4 years, 10 months old. The mean age at start for all children in the sample was just under 2 years, 6 months of age. One hundred twenty-nine children (60.8%) in the sample started receiving services under three years of age, and 83 children (39.2%) were between 3 and 5 years old.

A mean starting age for each of the 25 responding agencies in phase two was computed. These average ages at start by agency ranged from 10 months to 4 years and 4 months of age. Twelve agencies (48%) in phase two of the study began serving children averaging less than 3 years of age, while 13 agencies (52%) reported the average starting age of children was over 3 years old. Figure 8 illustrates the differences between counties for the average starting age of children served. While there are some observable differences between counties for average starting age, these differences are not statistically significant.

The average age of children at the start of a program did not vary greatly with referral source. Pediatricians, for example, referred 25 children over two

AVERAGE AGE AT START

Years at start

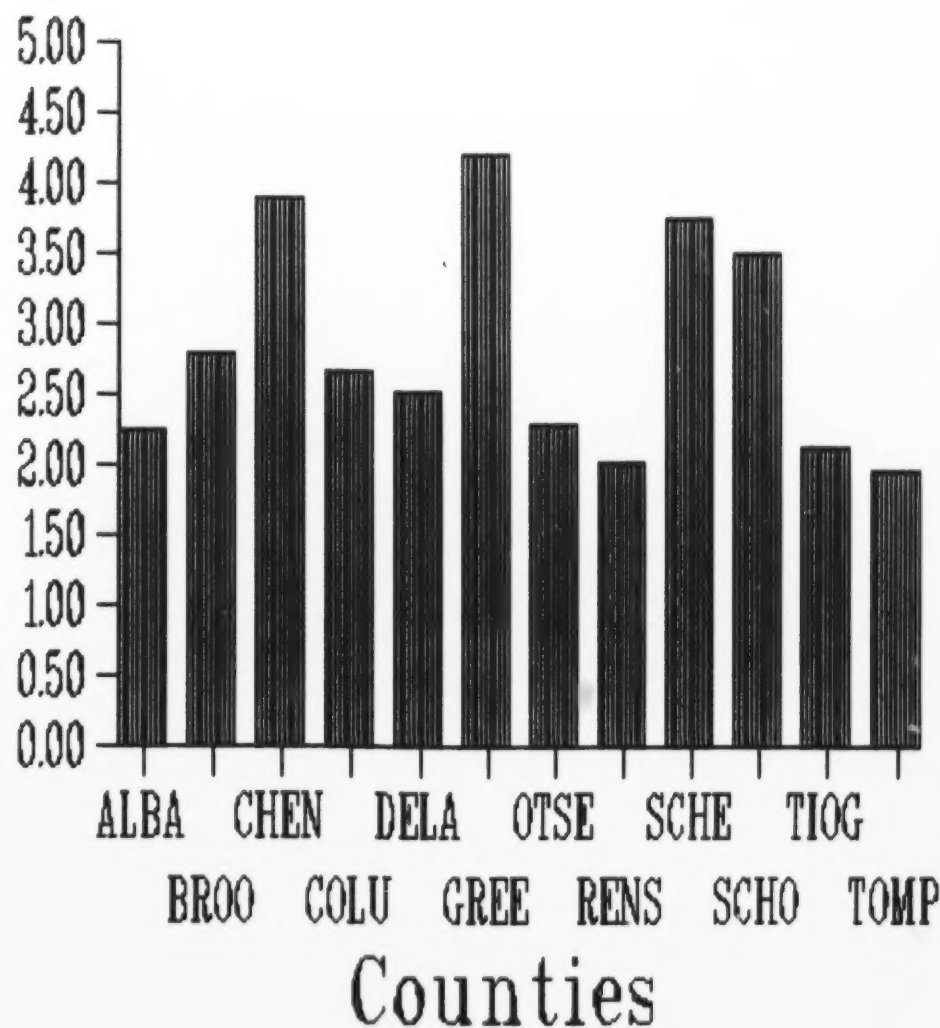


FIGURE 8

and a half years of age and 26 children under 2 and a half. Two referrals by pediatricians were just two and a half years old.

Waiting Time

One of the survey questions asked for the length of time that a child waited before starting program in an agency. Waiting times ranged from no time at all to a maximum of 22 months. The mean waiting time was just over one and a half months, while the median waiting time was one month. An analysis of variance was performed to see if waiting times varied significantly by referral source, age at start, or county of location. Each of these variables was expected to account for some of the variation in the length of time children waited prior to starting a program.

Table 5 shows that the majority of referral sources have no significant ($p=.05$) effect on waiting time. However, referrals by pediatricians, diagnostic centers, information and referral centers, and agencies' own efforts do produce substantially different waiting times. Pediatrician referrals have on average a two week shorter waiting period than the sample mean of 1.52. Those screened by and referred within the same agency waited an average of only two weeks before starting a program. Children referred by diagnostic centers and information and referral centers, on the other hand, waited approximately one month longer overall than children from all other referral sources. An analysis of variance showed that waiting time does not vary significantly by the child's age, $F(4, 207)=.940$, $p=.442$. This is in stark contrast to the effect of county location,

Table 5
MEAN WAITING TIME BY REFERRAL SOURCE

<u>Referral Source</u>	<u>Mean Waiting time*</u>	<u>F</u>	<u>(Prob.)</u>
ECDC	2.50	2.620	(.107)
Pediatrician	.96	7.330	(.007)
Diagnostic Center	2.30	8.640	(.004)
Hospital	2.10	1.400	(.237)
Info. & Ref. Center	2.60	4.800	(.029)
Preschool Program	1.20	.937	(.334)
Family/Self	1.80	.746	(.388)
Dept. Soc. Serv.	1.10	.598	(.440)
Other Health Prof.	1.25	.300	(.586)
Agency's own efforts	.50	4.361	(.038)

*Mean waiting time for sample = 1.52 months.

$F(11, 200)=5.45$, $p<.000$, though the strength of this relationship stems mainly from the protracted average waiting time of Tioga County, where the mean waiting period was nearly five and a quarter months.

In addition, the average waiting time for each agency was computed. Twelve agencies (48%) reported an average waiting time of 1 month or less. Thirteen agencies (52%) reported an average waiting time of from just over 1 month to just under 7 and one half months. Figure 9 illustrates the differences between counties for the average waiting time of agencies in each county.

Location

The children in the sample came from 22 counties. Most children were from Albany and Broome counties with 53 and 49 children, respectively, while Rensselaer County had 26 children in the study. The sample also included nine children who came from well outside the immediate vicinity of either DDSO, including 4 counties in New York City and 2 counties on Long Island. Overall, 44 children (20.8%) were served in a county other than the county in which they lived. Figures 10 and 11 illustrate the findings for out-of-county children overall and by individual county, respectively. Agencies in four counties reported serving no children from outside their home county, while Schenectady and Tompkins County agencies reported serving the highest percentage of out-of-county children in the sample.

These findings did not relate to the transportation problems identified as a part of the individual child questionnaire. Most of the transportation

AVERAGE WAITING TIME

Wait time to start
(Months)

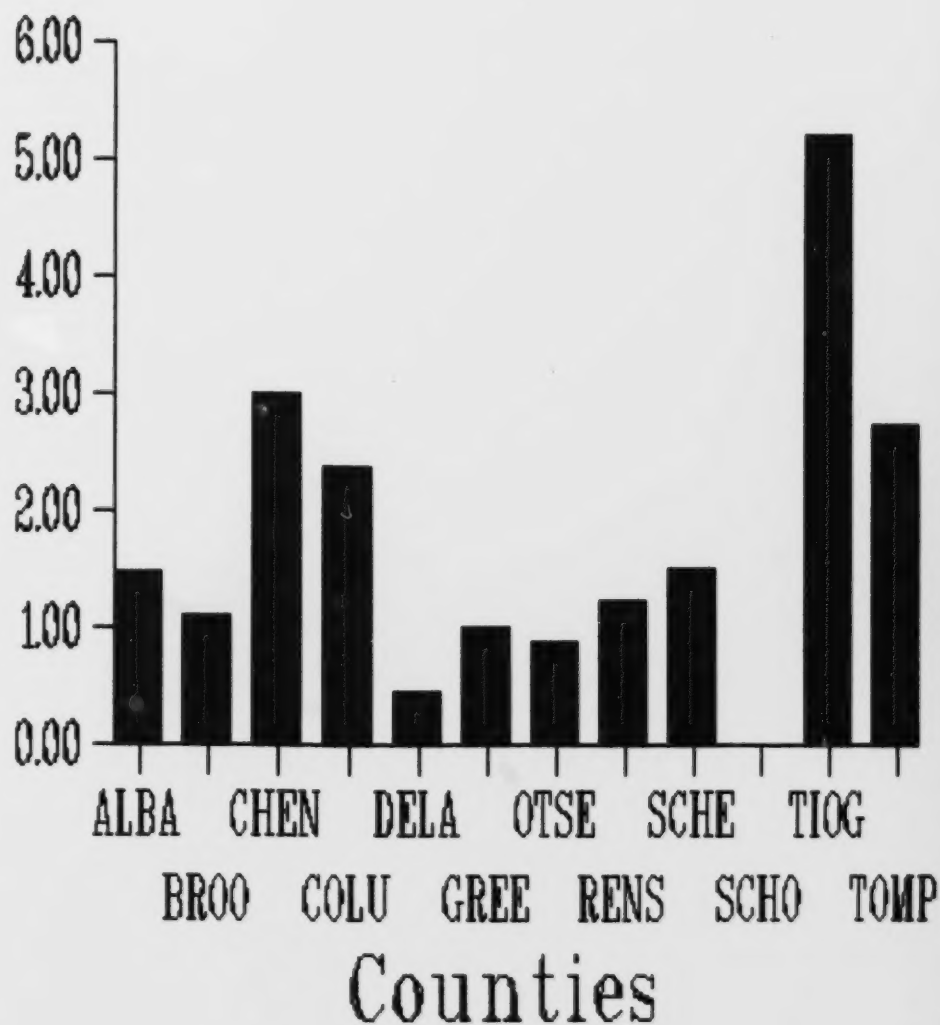


FIGURE 9

OUT OF COUNTY CHILDREN

As % of Total (N=212)

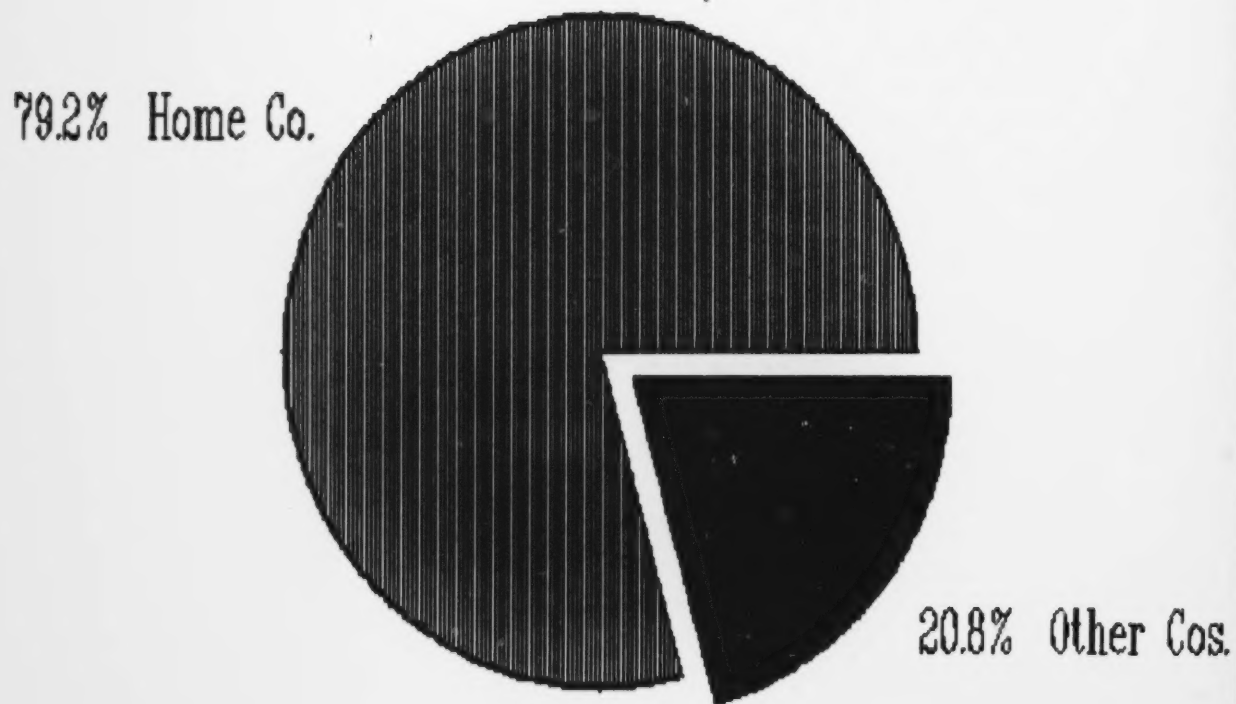
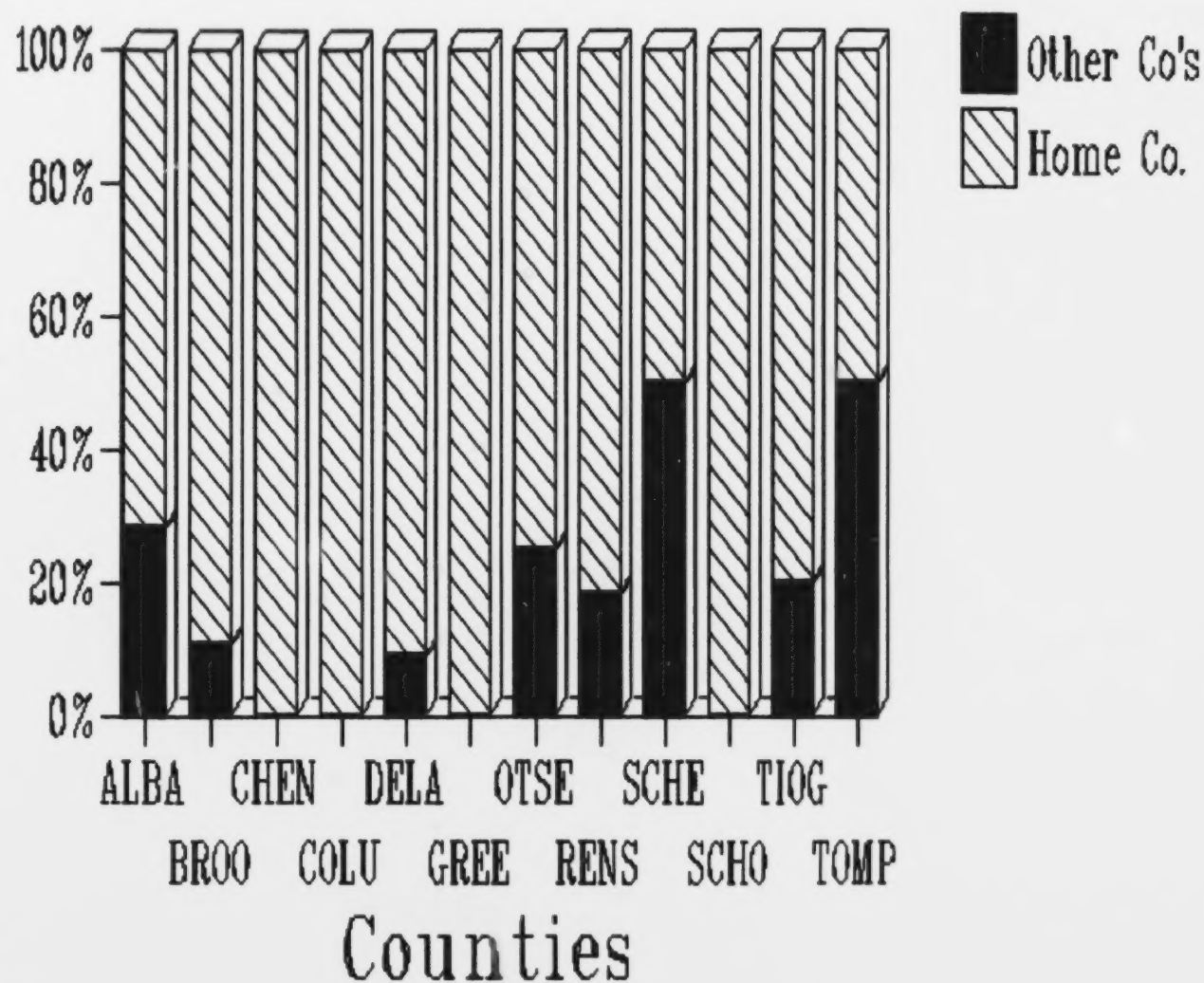


FIGURE 10

OUT OF COUNTY CHILDREN

% of Total Served



problems identified by providers occurred for children who received program services in the same county in which they lived.

Transportation Methods and Problems

Agencies were also asked to indicate how each child in the sample was transported to the agency for program. Information was not provided for 24 children (11.3%). Of the remainder (188), 61 children (32.4%) were transported by the agency's own vehicles, 58 (30.9%) were transported by vendors under contract with the agency, and 60 (31.9%) were transported by the child's parents (Figure 12). The differences between the three most frequently listed methods of transportation were negligible. Only 9 children (4.8%) were transported by some other means. These usually involved another agency, a public school bus, or the combination of the child's parents and some other person/professional.

In response to a question regarding problems with the child's transportation, agencies identified only 25 of the 188 children (13.3%) as having problems with transportation. Most of these problems occur in the O.D. Heck DDSO (16 of 25 or 64%) and about half overall (13 or 52%) are attributed to difficulties experienced with or by the parents. Twelve problems (48%) have to do with a variety of problems other than the parents: the funding for the transportation, the scheduling and service by vendors, the length of the ride (both in Albany County), or difficulties meeting the child's specific disability needs. Only two problems (8%) involved children who lived outside of the county in which they received services.

TRANSPORTATION METHODS

N = 188

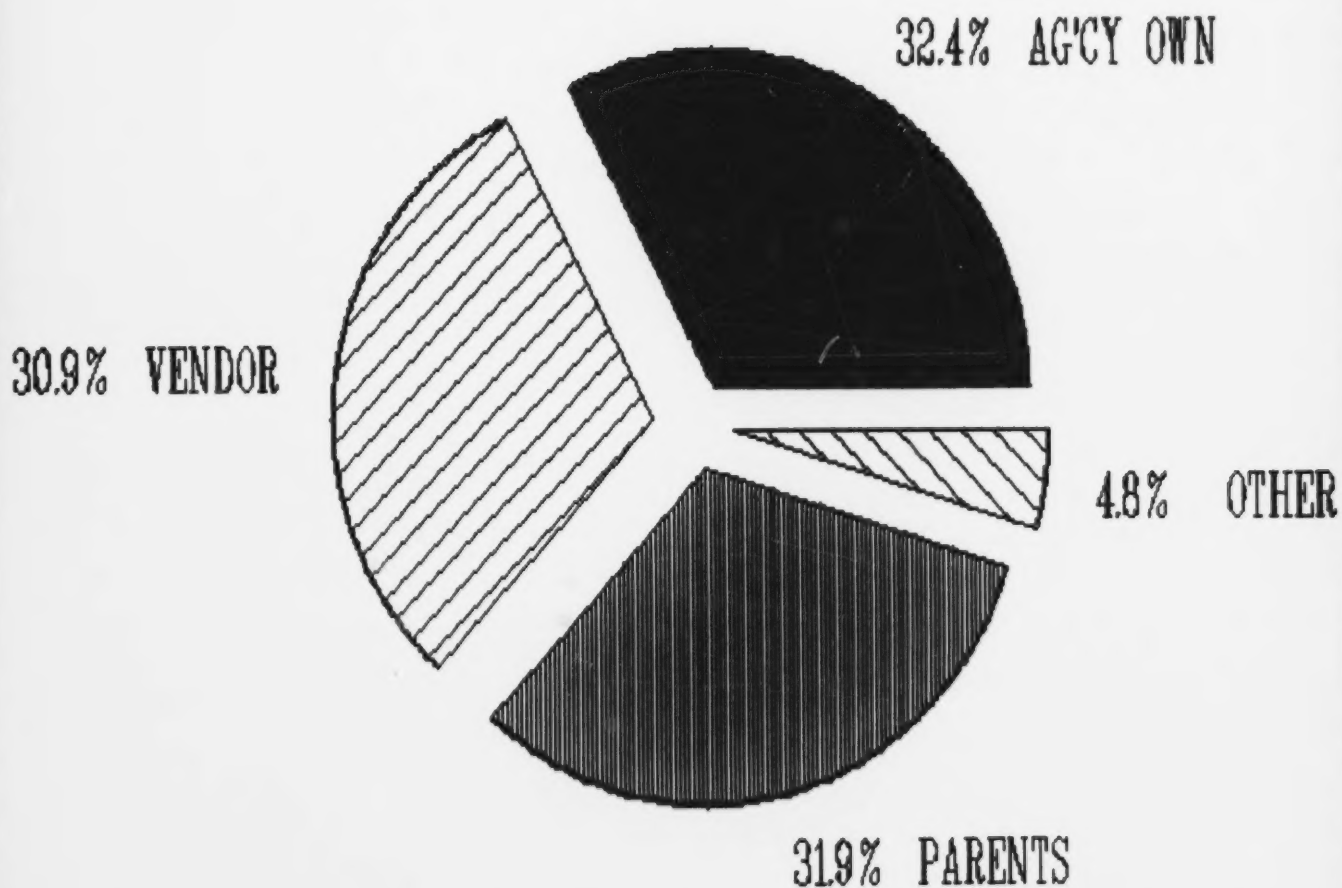


FIGURE 12

Summary

Pediatricians are the largest single source of referrals to programs and also are associated with significantly shorter waiting times from referral to start of program. Diagnostic Centers are the second largest source of referrals to programs but are also associated with significantly longer than average waiting times.

The average age at which children begin a service program is fairly uniform across the sample of agencies and counties. Children generally begin receiving services at 2 and a half years of age. The average age at start does not vary greatly with referral source.

Only one child in five receives services in a county outside of his/her home county. These out-of-county children do not account for the bulk of transportation problems identified by providers.

Agencies indicated that only a little more than 13% of children served had problems with transportation to services. Transportation methods were evenly split between agencies' own systems, vendors, and parents.

PROBLEMS AND OPPORTUNITIES

Finally, agencies in phase two were asked to respond to a problem inventory by rating the severity of a list of problems and concerns provided. The list was developed from the results of a consensus building exercise involving providers and consumers of early intervention services and government agency representatives in Monroe County. Respondents were asked to rate 26 problems and concerns using a scale ranging from "Not a Problem" to "Often a Major Problem." (See Appendix 2).

Table 6 shows the ranked results of the Problem Inventory in terms of the mean response for each problem. The response scale in the Inventory (1-5) was recoded so that 0 = "Not a problem", 1 = "Occasionally a minor problem," 2 = "Often a minor problem," 3 = "Occasionally a major problem," and 4 = "Often a major problem." Scores closer to 0 indicate less serious concerns, and scores closer to 4 indicate that agencies tend to see these problems as major problems more often.

Two problems were considered "Occasionally a major problem" overall. These included the lack of a legislative mandate which clearly indicates responsibility for this population and inadequate community education regarding the needs of disabled children (0-5) and their families. Other problems which came close to an average score of 3.00 were: lack of awareness among parents of community resources, and lack of available funds. The problems which providers felt to be the least critical were: the absence of a single point of entry into

Table 6

PROBLEM MEAN SCORES

<u>Problem</u>	<u>Mean score</u>
Lack of legislative mandate	3.00
Inadequate community education about needs	3.00
Lack of available funds	2.96
Lack of parental awareness of resources	2.96
Lack of info. about numbers and needs of at-risk	2.84
State agency responsibilities not defined	2.75
State efforts to deliver services not coordinated	2.65
Inadequate number of trained professionals	2.64
Limited access to policymakers	2.57
Family Court requires label absent in those at risk	2.56
Outreach inadequate to identify at risk children	2.54
Eligibility criteria differ among state agencies	2.42
Inadequate transportation services	2.28
Conflicting regulations	2.25
Lack of lead agency/organization	2.21
Funding sources not coordinated	2.13
Turf issues at executive levels of government	2.13
State agency's definitions of conditions are vague	1.92
Lack of communication among service providers	1.88
Lack of outcome measures	1.88
Agencies plan independently	1.76
Lack of trust among agencies	1.67
Competition for dollars	1.54
Diagnostic terms often misunderstood	1.50
Lack of predictors of later functioning	1.48
Absence of a single entry point	1.21

- 0 = Not a problem
 1 = Occasionally a minor problem
 2 = Often a minor problem
 3 = Occasionally a major problem
 4 = Often a major problem

the service system (1.2), clinicians lack reliable predictors of later developmental functioning (1.5), and diagnostic terms are often misunderstood (1.5).

A factor analysis was performed on the results of the Problem Inventory and yielded three factors which explained 56.7% of the variation in the responses. Examination of these three groups shown on the following page suggests similarities about the nature of each group of problems. Factor 1 seems to involve mostly problems of a state level. Factor 2 seems to involve mostly local issues, and factor 3 involves concerns that can be seen as resulting from problems in state-local interaction and communication. Table 7 lists the problem groups with the mean score for each group.

The problems which tended to group together are as follows:

Factor 1

State Problems

State agency responsibilities
not defined
Limited access to policymakers
Eligibility criteria differ
Conflicting regulations
Funding sources not coordinated
Turf issues in government
Agencies' definitions vague
Lack of outcome measures
Lack of predictors of later
developmental functioning

Factor 2

Local Problems

Inadequate community education
Lack of parental awareness of resources
Lack of information about numbers
of children at risk
Outreach inadequate to those at risk
Agencies plan independently
Lack of a single point of entry

Factor 3

State/Local Interaction Problems

Lack of available funds
Inadequate transportation services
Lack of communication among service providers
Diagnostic terms often misunderstood

(Several problems did not load singularly.)

Table 7

PROBLEM GROUPS and MEAN SCORES

<u>State Problems</u>	<u>Group Mean Score</u>
State agency responsibilities not defined	
Limited access to policymakers	
Eligibility criteria differ among state agencies	
Conflicting regulations	2.21
Funding sources not coordinated	
Turf issues at executive levels of government	
State agency's definitions of conditions are vague	
Lack of outcome measures	
Lack of predictors of later developmental functioning	
 <u>Local Problems</u>	
Inadequate community education about needs	
Lack of parental awareness of resources	
Lack of info. about numbers and needs of children at risk	2.33
Outreach inadequate to identify children at risk	
Agencies plan independently	
Absence of a single entry point	
 <u>State-Local Problems</u>	
Lack of available funds	
Inadequate transportation services	2.03
Lack of communication among service providers	
Diagnostic terms often misunderstood	
 Seven problems did not load singularly.	
0 = Not a problem	
1 = Occasionally a minor problem	
2 = Often a minor problem	
3 = Occasionally a major problem	
4 = Often a major problem	

Three problem index scores were developed for each agency by averaging the responses received from each agency for all problems in each group. Agency index scores were then averaged for each county to give an indication of the degree to which these problems differ from county to county. Lower scores indicate that these groups of problems are generally less of a concern for agencies in that county while higher scores indicate a greater concern in general. Figure 13 illustrates these problem index scores by county for each of the three groups of problems.

Local problems and issues are of greatest concern in four counties in the Broome DDSO: Broome, Chenango, Tioga and Tompkins. State level problems are of greatest concern in three counties, all in the O.D. Heck DDSO: Albany, Rensselaer, and Schenectady, while two other counties in the O.D. Heck area (Columbia and Greene) indicate little or no problems with these state level issues. Issues of communication and interaction between the state and local levels are clearly of greatest concern to agencies in Columbia, Delaware, Greene, and Schoharie counties. Otsego County ranked state-local issues only slightly above the other two groups of problems.

Summary

The kinds of problems perceived by providers can be organized into three

PROBLEM INDEX SCORES

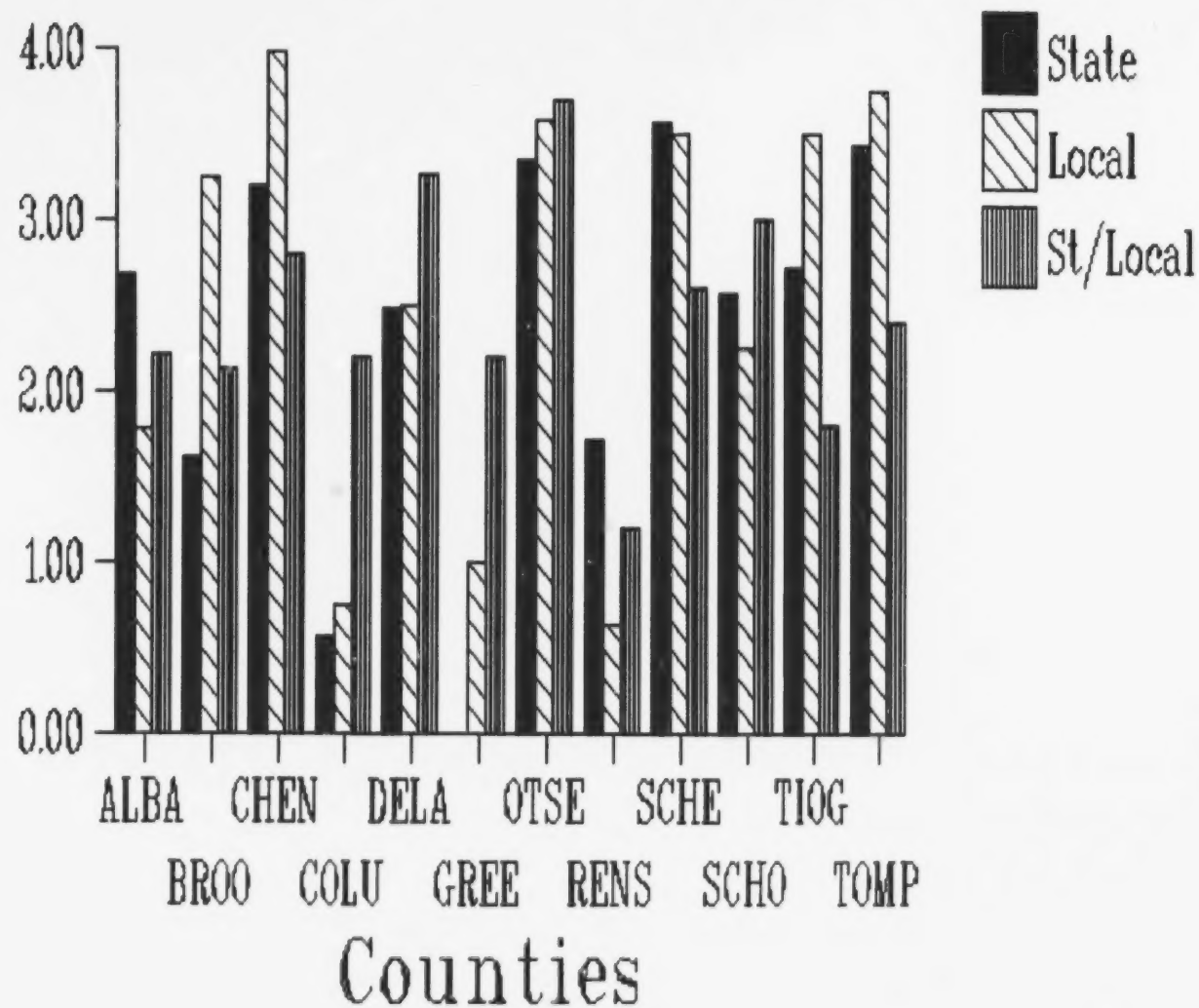


FIGURE 13

distinct categories: state level problems, local level problems, and problems that occur at the borders of interaction between the state and local levels. The most pressing perceived problem at the state level is one of a lack of definition of state agency responsibility for the preschool population. The most pressing perceived local problem is inadequate community education about the needs of disabled preschool children and their families. The biggest problem which providers perceive in the third category is the lack of available funds.

Local issues predominate in the Broome DDSO, while state level issues are of greatest concern for counties in the O.D. Heck DDSO.

DISCUSSION

INTRODUCTION

The study set out to examine and describe early intervention services in twelve counties in program jurisdictions of similar size and make-up. The two DDSOs involved in the study were chosen partly because of their similarities in size, urban-rural mix, socio-economic context, and inclusion of educational and medical centers within their boundaries. The primary goal of the project was a comprehensive description of program resources within these two DDSOs for children from birth to five years of age and a description of the linkages among these resources. Following are observations and conclusions about these services that can be drawn from this study.

DIFFERENCES AMONG SERVICES AND PROVIDERS

Service Availability

Services tend to be grouped into three categories: Entry Services, Direction Services, and Specialized Services. These patterns of services showed relatively little variation across counties with respect to their availability. Specialized Services were generally the least available group of services probably due to the cost of providing these services and the short supply of

professionals in each specialty. Results of this study indicate that more trained professionals in the areas of occupational, physical, and speech therapy would improve the general availability of such services statewide.

It should also be noted that most of the data collected for this study preceded the establishment of many family support respite programs across the state, and the availability of respite services within the group of Specialized Services has probably increased greatly. Occupational therapy and physical therapy services continue to be relatively scarce services according to the survey data as well as anecdotal reports from providers.

Some services are generally more available than others for a variety of reasons. The observation that some services are consistently not available from one county to another across the survey area is congruent with much of the testimony given at recent public hearings conducted by the Department of Health prior to New York's decision to participate in planning under P.L. 99-457.

Transportation

Survey data did not indicate that transportation services are significantly lacking. Indeed, the factor analysis performed on the service data grouped transportation with those other Entry Services generally in greatest supply. Responses to the Problem Inventory were consistent with the findings about the availability of transportation. Most providers did not see inadequate transportation services as a major problem. It was ranked overall as often constituting a minor problem. This is in contrast to much of the conventional

wisdom regarding the availability of this service. Anecdotal reports from key informants often focus on the hardship imposed on very young children who must be transported long distances in order to attend a program which is center-based.

One child in five lives in a county other than the one in which he or she receives services. However, programs reported transportation problems for very few children who lived out of county. Most transportation difficulties occur for children who live in the same county where they receive services.

While the study suggests that transportation services are not considered generally deficient, certain types of problems predominate. Most of the problems associated with transportation, according to providers, involve reliance on parents. However, providers expressed concern about the length of time very young children must spend on route to programs on agency or vendor vehicles. Other studies have shown that there is no clear advantage to center-based programming for the child (White and Casto, 1985).

Capacity and Coordination

The results of the analysis of waiting lists and available program slots were enlightening. Eight counties had many more children waiting than they had program spaces available indicating a need for greater capacity in those counties. Three counties reported having more program spaces open than they had children waiting to be served. Program directors indicated, however, that many of the program spaces available might not be appropriate for children on other

agency's waiting lists. The information in this study can be a helpful guide to identifying those areas where issues of capacity or coordination should be addressed.

Program directors indicated that it is often the policy of the program or agency not to create waiting lists or keep children on such lists. Instead the agency seeks an appropriate placement for the child who cannot be admitted to their program. The child is then considered to be receiving case management, advocacy, or information and referral services but may not be receiving other, more direct, therapeutic services.

This study indicates that issues of capacity or coordination vary from county to county within OMRDD's service regions. Therefore, the discussion focuses on either increased capacity or more effective coordination within each area of concern.

SOURCES AND PATTERNS OF REFERRAL

Referral Sources

Data collected about referral sources proved to be informative and significant in several ways. In terms of the number of referrals from various sources, pediatricians ranked highest while the Early Childhood Direction Centers ranked lowest. Pediatricians are often criticized by providers and advocacy groups for their failure to refer children in a timely way. The usual story involves the pediatrician who tells the parents not to be concerned; the

child will grow out of whatever delay the parents are anxious about. The results of this survey, however, indicate that perhaps this criticism is undeserved. One fourth of all referrals in the sample were made by pediatricians, ten percent more than the next largest referral source, diagnostic centers.

The relatively low number of direct referrals from the Early Childhood Direction Centers is puzzling. By all accounts from key informant interviews and others (Davidson et al, 1984), this network of direction services constitutes a valuable resource and referral method. It is possible, and key informants who have reviewed the results concur, that a large number of referrals reported under family/self as well as a large proportion of referrals from pediatricians may be attributable in part to the work of the ECDCs in letting parents and physicians know who to contact for services.

It is also clear from the results of the survey that there are many programs or persons which can act as referral sources for children with or at risk for developmental delays. The original survey listed what were felt to be the seven most often-used referral sources. The data received made it necessary, however, to reformulate the categories to include significant contributions from unexpected sources. There are a multiplicity of means by which children can be referred to programs and services.

Pediatricians play a key role in the identification and referral of preschoolers with developmental delays. Whether or not they are well-prepared for this role is a matter of some debate, but this study and others (Suelzle and Keenan, 1981) indicate that they are nevertheless important figures in the process of linking a child with developmental delays to programs and services.

Waiting Times

In addition, referrals from pediatricians correlated significantly with shorter waiting times. Children referred by a pediatrician waited two weeks less, on average, to start program than children from most other referral sources. Clearly, pediatricians are a very important resource for families of young children with developmental delays. Continued efforts are underway to educate these physicians regarding the need for early programming for children with developmental delays. This will have an impact on improving the effectiveness of early intervention services.

It is less surprising to find that an agency's own case finding efforts are significantly related to shorter waiting times. While children who are screened and referred on for services within the same agency wait an average of only two weeks before beginning services, most agencies did not report this type of case finding activity, and the number of children referred in this way was not large. Agency referral is a short and direct route to services but only for a fortunate few.

The only two referral sources significantly correlated with longer than average waiting times for those referred were diagnostic centers and information and referral programs. These two sources account for over one-fifth of all referrals. It may be that the testing procedures used or the goal of providing a multidisciplinary team evaluation through the diagnostic center requires

significantly more time. Diagnostic centers are relatively scarce around the state and often perform their functions on a regional basis. Anecdotal reports from the Broome-Tioga Community Clinic, for example, indicate that they have seen children from as far away as St. Lawrence and Franklin counties. The referrals from these centers may be delayed because they are "long distance" referrals without a direct, local follow-up. The OMRDD has recently opened a new diagnostic and assessment program in the Syracuse DDSO, the Margaret Williams Center, which is modeled in part after the successful Broome program.

The referrals from information and referral programs may be delayed because of the intervening steps required to use that program as a "middleman" in securing services. The multiplicity of these programs may also affect the speed with which they can provide services. Parents who think they have reached a comprehensive information and referral service that can direct them quickly to the most appropriate program may find that they must wait while that I & R contact becomes knowledgeable about the services available to meet that particular child's needs. (Downey, Castellani, and Tausig, 1985.)

Linkages

The results with respect to previous service history raise questions about the adequacy of linkages within the service system. Agencies were unable to report the previous service history for nearly one-third of the children in the

sample. This is unfortunate, because data about those whose history is known indicates that previous services are likely to have been provided by another preschool program or some type of medical program.

It is clear that there is a need to refer all relevant data about a child, to follow-up on referrals to be sure that the child's history is passed along, and to ask for more historical data as part of standard intake procedures.

PROBLEMS AND OPPORTUNITIES

There are some patterns to the way in which the problems surveyed group together across county or DDSO lines. The Broome DDSO seems overall to have a greater concern with local issues than the O.D. Heck DDSO ranking local problems higher than state level problems in all six counties. State level problems are seen as more critical to three counties in the O.D. Heck DDSO, but two counties in this DDSO rank state level problems as the lowest. In view of the controversy concerning funding through Family Court in Albany County during the time of the survey, the greater concern for state level issues over local issues may indicate that the providers see a solution as coming from state action rather than local efforts. Counties with large urban centers were split along DDSO lines with the Broome counties (Broome and Tompkins) indicating local problems to be the most pressing and the O.D. Heck counties (Albany, Rensselaer and Schenectady) citing state level problems as the most difficult. Counties

which are mostly rural (Columbia, Delaware, Greene, Otsego and Schoharie) see the problems of state-local interaction, including transportation problems, as being of greatest concern.

The major problems identified by providers, administrators and advocates (Albert Einstein College of Medicine, 1986) and rated in this study may be dealt with as a result of recent federal legislation and New York State's response to that legislation. Public Law 99-457 offers the first step in developing a mandate to provide services to children from birth to five. Providers in this study saw the lack of a legislative mandate as one of two of the biggest problems affecting their ability to serve young children with developmental delays.

CONCLUSION

This study set out to examine the preschool early intervention service system in twelve counties within two OMRDD service districts. The goal of the project was to describe existing programs in terms of some of their major characteristics as well as to identify some of the problems and issues in this area and their relationship to the service environment.

The findings of this study include a way of grouping services, an examination of the availability of services, a list of the wide variety of referral sources, the effect of referral source on waiting time, and the major problems identified by providers.

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APPENDIX 1
Services Inventory Form

**INVENTORY OF SPECIALIZED SERVICES
for Children Birth to Five**

1. Agency name: _____

(Please complete a separate inventory for each program that the agency operates.)

2. Program name: _____

3. Program address: _____

Zip _____

4. Phone: _____

5. Contact person: _____

6. Counties served: _____

7. Number of clients served in this program from 9/1/84 to 9/1/85 (unduplicated count):

a. Total _____ b. Age breakdown: 0-2 _____ 3-5 _____ 6+ _____

c. Does this include services provided in July and August ('85)?

1. Yes 2. No

8. a. Is there a waiting list for this program? 1. Yes 2. No

b. If Yes, approximate number waiting: _____

c. If No, how many more can this program accommodate? _____

c.1. If applicants or referrals have not been admitted to this program, list reasons: _____

9. Is there a waiting list for a specific service(s) in this program?

1. Yes 2. No If Yes, give details: _____

10. Services (see attached definitions)

Circle Y or N to indicate if this program provides each service. Write the number receiving each service from 9/1/84 to 9/1/85 in Column 2. Of those served in Column 2, what percentage had a developmental delay (Column 3)? What percentage (of Column 2) were "at risk" (Column 4)?

Services	1 Provided?		2 Number	3 % Dev. Delay	4 % At Risk
Advocacy	Y	N	_____	_____%	_____%
Audiology	Y	N	_____	_____%	_____%
Case Management	Y	N	_____	_____%	_____%
Counseling	Y	N	_____	_____%	_____%
Diagnosis/Assessment	Y	N	_____	_____%	_____%
Education	Y	N	_____	_____%	_____%
Funding*	Y	N	_____	_____%	_____%
Info. & Referral	Y	N	_____	_____%	_____%
Medical/Nursing	Y	N	_____	_____%	_____%
Occupational Therapy	Y	N	_____	_____%	_____%
Parent Training	Y	N	_____	_____%	_____%
Physical Therapy	Y	N	_____	_____%	_____%
Psychology	Y	N	_____	_____%	_____%
Respite	Y	N	_____	_____%	_____%
Screening	Y	N	_____	_____%	_____%
Social Work	Y	N	_____	_____%	_____%
Speech Therapy	Y	N	_____	_____%	_____%
Transportation	Y	N	_____	_____%	_____%
Other (specify):					
_____	Y	N	_____	_____%	_____%
_____	Y	N	_____	_____%	_____%

*Please specify which services were funded: _____

INVENTORY OF SPECIALIZED SERVICES

for Children Birth to Five

SERVICE DEFINITIONS:

ADVOCACY - assisting the family of a child with a disability or developmental delay to obtain services and/or entitlement funding (e.g. SSI, Medicaid) through direct contact with agencies on the family's behalf or through support of a family in processes involving Family Court petitions and Committees on the Handicapped.

AUDIOLOGY - those activities which include the assessment of hearing loss and receptive and expressive language disorders, comprehensive audiological screening, speech audiometry, assessment using visual cues, assessment using amplification, and the procurement, maintenance, and replacement of hearing aids.

CASE MANAGEMENT - those activities which ensure the integration of services for maximum effectiveness and minimal duplication, and the implementation and provision of services not provided by the program as needed and indicated in the child's educational or program plan.

COUNSELING - individual or group therapeutic sessions involving the family and/or the child with the goal of supporting or improving the family's ability to cope with their child's disability or developmental delay.

DIAGNOSIS/ASSESSMENT - those services which involve the determination of the nature and extent of a child's disabling condition including his/her physical, mental, and social abilities and the degree to which the disability can be expected to limit daily living and educational activities.

EDUCATION - the provision of special education services by certified teachers and teachers' aides in accordance with NYS Education Department guidelines for education services.

FUNDING - the provision of local assistance, state education, local county tax monies, or public or private grant monies to individual families or to certified providers for the purpose of obtaining needed and indicated intervention, educational, and related services for a child with a disability or developmental delay.

INFORMATION AND REFERRAL - those activities which provide agency clients as well as the general public with one-to-one descriptions of available and accessible services both within that agency and at other agencies and the names and means of contacting the providers of those services.

MEDICAL/NURSING - those activities which maintain the general health conditions of individual children in the program and ensure preventive health measures such as: supervision, consultation, inspection, examination, assessment, prescription, immunization, disease control, and seizure management.

OCCUPATIONAL THERAPY - those activities which preserve and improve abilities for independent functioning such as range of motion, strength, tolerance, coordination, and activities of daily living; and prevent progressive disabilities using orthotic and prosthetic appliances, assistive and adaptive devices, positioning, behavior adaptation, and sensory stimulation.

PARENT TRAINING - those activities which prepare and support the parent(s) of a child with a disability or developmental delay to incorporate specific intervention and educational techniques in their daily activities with the child.

PHYSICAL THERAPY - those activities which preserve and improve abilities for independent functioning such as gross and fine motor skills, range of motion, muscle tone, endurance, coordination, perceptual and sensory motor skills, activities of daily living, and mobility.

PSYCHOLOGY - those psychological and related services which are directed toward improving the intellectual, social, and emotional development and functioning of children with disabilities or developmental delays through assessment, diagnosis, evaluation, planning and implementation of service programs and consultation with families and provider staff.

RESPIRE - the provision of alternative residential or custodial care specifically for the purpose of allowing the family of a child with a disability or developmental delay to meet an emergency situation, to complete necessary personal tasks, or to obtain short-term relief from the burden of caring for the child.

SCREENING - those activities and services which an agency provides to determine whether a child should be referred for further assessment and evaluation when the child is at risk of or suspected of having a developmental delay.

SOCIAL WORK - the application of social work methods directed toward stabilizing and improving the social functioning of a child with a disability or developmental delay and his/her family including such activities as individual counseling, group counseling, family counseling, and interpersonal skills training.

SPEECH THERAPY - those activities designed to stimulate language acquisition and expression, comprehensive speech and language remediation, and interpretive services and devices for the deaf as appropriate.

TRANSPORTATION - the provision of service to, from, and between a child's residence and the facilities, programs, and resources specified in his/her special educational or program plan as well as necessary ancillary services.

DEVELOPMENTAL DISABILITY - a severe, chronic disability of a person which (a) is attributable to a mental or physical impairment or combination of mental and physical impairments; (b) is manifested before the person attains age twenty-two; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; (e) reflects the person's need for a combination and sequence of special inter-disciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

APPENDIX 2
Child Data Instrument &
Problem Inventory Instrument

PROVIDER QUESTIONNAIRE - CASE REVIEW
Special Services for Children Birth to Five

agency
code

The following questions refer to the cases which you were asked to select. Please answer them by referring to the case record for your information. We will ask for no identifying information about the child, and all information will be kept strictly confidential. Please complete one questionnaire for each case selected.

1. Which of the following referred this child to your program?

1. Early Childhood Direction Center
2. Pediatrician
3. Diagnostic center or clinic
4. Hospital (if other than #3 above)
5. Information and referral agency
6. Another pre-school program
7. Family self-referral
8. Other (specify): _____

2A. Are you able to provide information about where this child received services before coming to your program?

1. Yes (Answer 2B.)
2. No

2B. If Yes, please list other services received and from whom: _____

3. How old was this child when he/she started to receive services from your program?

_____ years _____ months

4. How much time elapsed between the time the child was first referred and when the child began receiving direct services?

_____ months (If less than 1 month, write 0.)

5. Please give the zip code of the child's home address: _____

6A. How does your agency provide transportation for this child to your program? (Circle one.)

- | | |
|-------------------------------------|----------------------------------|
| 1. Agency or program's own vehicles | 3. Parent(s) transport the child |
| 2. Provided by a vendor | 4. Other (Specify): _____ |

6B. Are you aware of any transportation difficulties connected with getting this child to your programs?

1. Yes (Answer 6C.)
2. No

6C. If Yes, please explain: _____

PROVIDER INTERVIEW

PROBLEM INVENTORY

Indicate to what extent the following are problems for your agency as a provider of services to children birth to five years of age by circling after each statement the number of the one response that typically describes your experience.

	<u>Not a problem</u>	<u>Occasionally a minor problem</u>	<u>Often a minor problem</u>	<u>Occasionally a major problem</u>	<u>Often a major problem</u>
Outreach services for identifying at risk children are inadequate	1	2	3	4	5
Lack of a legislative mandate which clearly indicates responsibility for this population.	1	2	3	4	5
Criteria for determining eligibility to receive services differ between state agencies and funding sources.	1	2	3	4	5
State agencies' definitions of handicapping conditions are vague or conflicting.	1	2	3	4	5
Competition for dollars due to rapidly expanding pre-school population	1	2	3	4	5
Clinicians lack reliable predictors of later developmental functioning	1	2	3	4	5
The absence of a single point of entry into the service system.	1	2	3	4	5
Funding of services through the Family Court system requires a label of "handicapped" based on a diagnosis which is absent in children who are determined to be "at risk."	1	2	3	4	5
Lack of communication among service providers	1	2	3	4	5
Lack of awareness among parents of community resources.	1	2	3	4	5
Lack of available funds.	1	2	3	4	5

	<u>Not a problem</u>	<u>Occasionally a minor problem</u>	<u>Often a minor problem</u>	<u>Occasionally a major problem</u>	<u>Often a major problem</u>
Inadequate transportation services.	1	2	3	4	5
State agency responsibilities for this population are not well defined.	1	2	3	4	5
"Turf" issues at the executive level of state, county, and local governments.	1	2	3	4	5
Lack of guidelines to measure outcomes of pre-school services.	1	2	3	4	5
Conflicting regulations.	1	2	3	4	5
Federal, state, and local funding sources are not coordinated.	1	2	3	4	5
Inadequate numbers of trained professionals to provide services to unserved populations.	1	2	3	4	5
Diagnostic terms are often misunderstood.	1	2	3	4	5
State agency efforts to deliver services to this population are not well coordinated	1	2	3	4	5
Lack of trust among agencies.	1	2	3	4	5
Inadequate community education regarding the needs of disabled children (0-5) and their families.	1	2	3	4	5
Limited access to state policy makers.	1	2	3	4	5
Agencies engage in long range planning independently.	1	2	3	4	5
Lack of a lead agency/organization to develop and maintain a coordinated system of services.	1	2	3	4	5

	<u>Not a problem</u>	<u>Occasionally a minor problem</u>	<u>Often a minor problem</u>	<u>Occasionally a major problem</u>	<u>Often a major problem</u>
Lack of information about the numbers and needs of children at risk.	1	2	3	4	5
Other (specify): _____	1	2	3	4	5
_____	1	2	3	4	5
_____	1	2	3	4	5

Respondent name: _____

Agency: _____

County: _____